



June 26, 2020

The Honorable Lamar Alexander  
Chairman  
Senate Committee on Health, Education, Labor and Pensions  
428 Senate Dirksen Office Building  
Washington, DC 20510

**RE: Comment on *Preparing for the Next Pandemic* White Paper**

Dear Chairman Alexander,

The National Organization for Rare Disorders (NORD) thanks the Committee on Health, Education, Labor and Pensions for the opportunity to provide comments on the *Preparing for the Next Pandemic* white paper released on June 9, 2020.

NORD is a unique federation of voluntary health organizations dedicated to helping the 30 million Americans living with a rare disease. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. NORD aims to ensure that the perspective of the patient is considered each time decisions that can impact the health care system are made. NORD appreciates the opportunity to convey perspective of the rare disease community on the impact of public health emergencies and natural disasters as these patients are often heavily dependent on a functional health care system to thrive and are likely to experience exacerbated health consequences when health care services become inaccessible.

The COVID-19 pandemic has been particularly challenging for the rare disease community. Many rare disease patients are immune-compromised, putting them at high risk of infection and serious illness. In April and May of this year, NORD, alongside our Rare Action Network Ambassadors, hosted COVID-19 Virtual Discussion Groups across all 50 states which provided an opportunity for rare disease patients, caregivers, providers and other stakeholders to share their experiences with COVID-19 and the health care system during the pandemic. Discussion group participants shared the challenges and benefits of increased access to telehealth, fears of discrimination and the lack of accessible personal protection equipment as some of their chief concerns. They also highlighted the strain the pandemic was putting on their mental health and ability to participate in their clinical trials.

As this pandemic continues, NORD is committed to ensuring that the rare disease community's concerns are addressed through legislative or regulatory action and that the lessons learned this pandemic are incorporated into these policies. NORD's comments will center on the questions related to public health capabilities, specifically to telehealth. NORD also reiterates the coalition comments we joined dated July 26, 2020.



## **Tests, Treatments, and Vaccines**

Experts agree that access to testing, treatment, vaccines, and recovery services are the most important part of slowing and stopping the spread of COVID-19. We appreciate the work that has been done so far. One of the critical steps that must be taken, once more tests, treatments, and vaccines are more broadly available, is that all individual and group market insurance must be required to cover all care related to the testing, treatment, vaccines and recovery services from the COVID-19 virus without cost sharing for consumers. It is critical that testing, treatment, vaccines, and recovery services are provided at no-cost to consumers, regardless of their method of coverage. Removing all cost-related barriers to treatment will ensure that the greatest number of people take action to care for themselves and those around them as this highly contagious virus spreads. Applying these same coverage standards to protect individuals already enrolled in non-compliant plans, like short-term, limited duration (STLD) and association health plans (AHP), is also important to robustly protect individuals, families, and the public health. As Congress assesses expanding coverage of these key services, increasing the costs insurers will be obligated to pay, it is critical that the appropriate risk mitigation strategies (further explained in this letter) are implemented to ensure premiums remain affordable for patients and consumers in the future

## **Stockpiles, Distribution, and Surges**

### **Stockpiles and Discrimination**

Appropriate stockpiling of critical equipment, including personal protective equipment (PPE) and medical supplies such as ventilators, as well as improved distribution of these resources is critical.

The reality is that it is the rare disease population that might need aggressive and direct intervention to survive COVID-19, yet in a situation where resources are scarce, states and hospitals have been forced to use worst case scenario planning to guide health care providers on how to allocate scarce resources and medical equipment--decisions that no providers would ever want to have to make. NORD learned that, in developing this guidance, some states and hospitals are considering crisis standards of care or triage plans that could discriminate against people with underlying medical conditions.<sup>1</sup>

Under the Americans with Disabilities Act (ADA), civil rights protections are extended to the vast majority of those with rare diseases, who may have visible or invisible disabilities. On March 28, the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services issued a bulletin regarding Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19). In the bulletin, OCR reminded federally-funded health programs and activities that Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act prohibit discrimination on the basis of disability, and that these civil rights laws are still in effect. OCR continues, “persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities or age.

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<sup>1</sup> <https://publicintegrity.org/health/coronavirus-and-inequality/state-policies-may-send-people-with-disabilities-to-the-back-of-the-line-for-ventilators>.



Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.” Regardless of this guidance, patient advocates in more than a dozen states filed complaints out of concern that their state’s crisis of care plans were discriminatory against those with chronic conditions or disabilities during the first few months of the COVID-19 crisis. The implementation and strong enforcement of this guidance is necessary to protect rare disease patients and ensure they have access to the care that they need.

As the COVID-19 pandemic continues and future natural disasters and health emergencies occur, it is important that non-discrimination laws are in place and enforced, but avoiding a situation where critical resources like PPE and ventilators are scarce in the first place is vital to ensuring rare disease patients are not discriminated against during this or future health emergencies. Furthermore, access to PPE outside of a hospital setting is particularly important for rare disease patients as they often require home health services to maintain their health. If home health agencies and other ancillary health care services providers are unable to procure necessary PPE, many rare disease patients will forego care or treatment services to try to protect themselves, which can result in negative health outcomes and can further tax an already overwhelmed health care system. It is important to stockpile necessary resources not just for hospital and health facilities, but for the entire ecosystem of health care providers.

## **Public Health Capabilities**

### **Telehealth**

In the face of the COVID-19 pandemic, many rare disease patients have been at higher risk if they leave their homes for their routine medical appointments. Patients and physicians are increasingly looking to utilize telemedicine as a way to keep themselves safe in the midst of this crisis. Many rare disease patients travel significant distances, often across state lines, to obtain care from their routine health care providers, so they have benefited from state’s adjusting their provider licensure requirements to enable out of state providers to provide telehealth services during this pandemic.

While many rare disease patients have expressed relief and satisfaction at their ability to utilize telehealth services during the COVID-19 pandemic, it is incumbent on Congress and the Administration to pursue legislation and policies that put patient choice at the center of the debate about which aspects of telehealth to make permanent. Therefore, NORD urges the Committee to consider the following when determining permanent changes around telehealth or in advance of the next natural or public health disaster:

- ***All patients should have equal and effective access to telehealth services.*** Section 1834(m) of the Social Security Act should be waived or permanently modified to enable telehealth access for Medicare patients who are not located in rural areas. The Federal government should provide resources to support information technology infrastructure improvements where they are needed to ensure patients in both rural and urban areas benefit from telehealth services. Audio only connections should be permitted under telehealth coverage and adequate reimbursement.



- ***Patient choice must be preserved.*** Patients should not be pushed to or away from telehealth by their health plans or providers. 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, not provider reimbursement or patient cost-sharing requirements.
- ***Transparency around privacy protections and cost sharing must be established and preserved.*** Patients need to be confident that the technologies they are using for the telehealth visit are HIPAA compliant and/or FDA approved or cleared. Patients need to be made aware of the cost-sharing associated with their telehealth visit.
- ***Data should drive decisions on telehealth.*** Federal and state governments should collect and analyze data on the impact of telehealth on utilization, quality, health outcomes, and spending during the COVID-19 pandemic and after the pandemic abates to ensure high quality care is provided; positive health outcomes are achieved; and fraud is prevented.

### Paid Leave

The Centers for Disease Control (CDC) has advised those at high risk for severe illness from COVID-19 to continue to shelter in-place to protect their health during our current pandemic. However, under existing emergency paid leave policies legislated in the Families First Coronavirus Response Act, workers are only eligible for up to two weeks of financial support and job protection through expanded paid sick leave. Additionally, the legislated paid family medical leave program only provides support to those with children or adults with disabilities whose local school district or usual care providers are closed due to the pandemic for up to 10 weeks.

The reality is that these provisions do not provide adequate protection to many in the rare disease community and leave them and their loved ones with terrifying options to either quit their jobs and lose any employer-sponsored health care benefits or risk their health and the health of their loved ones by returning to work in a pandemic. Retaining employer sponsored coverage is critical for many rare disease patients given the specialized care they often receive, so quitting their jobs is often not an option, but without access to some form of paid leave, they are at increased risk of exposure and serious illness when forced to leave home for work.

As you develop policy proposals for the next pandemic and continue to work on responding to COVID-19, NORD encourages you to make the following changes to the paid family and medical leave program created in the Families First Coronavirus Response Act:

- Expand eligibility for paid family leave to include anyone who, because of a serious health condition that places them at grave risk from COVID-19, has been advised by their physician to remain home;
- Expand eligibility for paid family leave or additional financial support to include anyone who has been advised by a physician to remain home because there is a member of their household who has a serious health condition that places them at grave risk from COVID-19;



- Remove the arbitrary time limit on paid leave to ensure that these individuals can remain home as long as the COVID-19 pandemic poses a risk to their health and wellbeing; and
- Ensure this program applies to employers of all sizes.

#### Ensuring Adequate and Accessible Coverage during a Pandemic

NORD's recommendations would not be complete without acknowledging the importance of continuous and comprehensive insurance coverage. Individuals who are uninsured are less likely to seek testing or treatment if they are exposed to a virus like COVID-19 due to fears about the cost of care. This puts all Americans, but especially rare disease patients who may have compromised immune systems at risk. As Congress prepares for the next pandemic, we encourage further consideration of what flexibilities are needed to ensure that all individuals are able to receive necessary health care. For example, improving government subsidies to individuals enrolled in COBRA or the ACA's health insurance marketplace plans may help rare disease patients who lose their jobs during a public health emergency to stay on their health plan. A nation-wide special enrollment period for the federally-facilitated individual marketplaces are another avenue through which individuals may either gain or maintain insurance coverage during a pandemic.

Finally, it is critical that states are not pushed to make cuts to their Medicaid programs during a pandemic due to budget pressure. State Medicaid programs provide a vital safety net during a national public health crisis by covering traditionally underserved populations and helping to treat those infected with the virus. However, the increase in enrollment and costs puts significant strain on state budgets. An automatic and significant Federal Medical Assistance Percentage (FMAP) increase, coupled with stringent maintenance of effort provisions, would help states to maintain robust programs during a future crisis.

NORD once again thanks the Committee for the opportunity to comment on this white paper. We look forward to continuing to work with alongside you and your staff to ensure that the issues and barriers faced by rare disease patients and their caregivers are taken into strong consideration in preparation for the next wave of COVID-19 or future pandemics and natural disasters. For questions regarding NORD or the above comments please contact Heidi Ross at [HRoss@rarediseases.org](mailto:HRoss@rarediseases.org).

Sincerely,

Rachel Sher  
Vice President, Policy