



June 26, 2020

The Honorable Bill Lee  
Governor  
State Capitol, 1<sup>st</sup> Floor  
Nashville, TN 37243

**Re: NORD Support to Extend Executive Order #36**

Dear Governor Lee,

On behalf of the 1-in-10 individuals in Tennessee with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to extend Executive Order #36 (E.O. 36) which is set to expire on June 30, 2020. E.O. 36 provided several helpful legislative and regulatory flexibilities that allowed the rare disease community to maintain access to their much-needed health care and medications during the COVID-19 pandemic.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Rare diseases are present across a broad spectrum of medical conditions. For example, there are more than 500 types of rare cancers and all forms of pediatric cancer are rare. For patients suffering from these and numerous other rare conditions, it can take several years to receive an accurate diagnosis and effective treatment. Further, only a handful of rare diseases are well-understood, and many are immunocompromised leading to greater risk of infection due to COVID-19.

As a result, NORD urges you to take the following actions with respect to E.O. 36:

- **Extend Section #2:** This allows for out-of-state health care providers to practice telemedicine across state lines. Many rare disease patients travel significant distances, often out of their state, to obtain care from their routine health care providers, so they have benefited from Tennessee adjusting their provider licensure requirements to enable out of state providers to provide telehealth services during this pandemic.
- **Extend Section #3:** This allows for patients to fill a 90-day supply of their prescription to avoid exposure to COVID-19 with frequent trips to their pharmacy. As a result, this has helped avoid the risk of COVID-19 for countless rare disease patients.



- **Extend Section #34:** This adjusts TennCare policies to prevent coverage disruptions. Similar to many Tennessee residents, some rare disease patients rely on Medicaid for their health care insurance and additional flexibilities have prevented disruptions in care.
- **Extend Section #37:** This encourages health care insurance carriers to improve access to COVID-19 treatment, screening, and testing, which are all crucial to contain the virus. All patients, including rare disease patients should have access to affordable and accessible testing and treatment for COVID-19.
- **Extend Section #38:** This extends access for telemedicine, including expanding providers that are permissible to practice via telehealth. Some rare diseases require occupational and physical therapy and the opportunity to maintain access during COVID-19 via telemedicine has been crucial. If this is rolled back now, it would cause disruptions in case for those that have been relying on it.

Once again, on behalf of the Tennessee rare disease community, we thank you for considering extending EO 36. Please consider swiftly acting to extend the order before it is too late. For any questions, please feel free to contact me via email at [hross@rarediseases.org](mailto:hross@rarediseases.org). Thank you for your consideration.

Sincerely,

A handwritten signature in black ink that reads "Heidi Ross".

Heidi Ross  
Director of Policy

A handwritten signature in black ink that reads "TJBichell".

Terry Jo Bichell  
Rare Action Network  
Tennessee Volunteer State Ambassador