



December 1, 2020
Lori Shibinette
Commissioner
Department of Health and Human Services
129 Pleasant St
Concord, NH 03301

Dear Commissioner Shibinette:

On behalf of the 1-in-10 individuals in New Hampshire with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) is grateful for your efforts to address the threats and health challenges posed by COVID-19. We write today to follow up on our previous correspondence on August 10, 2020.

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.

NORD appreciated the opportunity to partner with several patient advocacy and disability rights organizations in [providing comments](#) on New Hampshire's draft crisis standards of care clinical guidelines. We write today to request that the state act now to finalize the crisis standards of care guidelines so they can be promptly operationalized to benefit the health and well-being of patients. We would like to reiterate the importance of incorporating our recommendations into the final crisis standards of care guidelines. Although we appreciate the state's attempt to be transparent in the work of the SMDAC (State Disaster Medical Advisory Committee) as they create the crisis standards of care plan, there should also be an expectation that all hospitals and healthcare providers are transparent in their individual plans, which must be guided by the SMDAC finalized guidelines. Transparency is extremely important as it helps to promote public trust and strives to ensure that the information being shared is reliable and straightforward. Therefore, the state should also provide links to all individual hospital and healthcare provider crisis plans on the SMDAC website.

Transparency and accessibility go hand in hand. It is critical for accessibility to be another priority in the crisis standards of care plan. The public cannot properly follow the protocol if the information being presented is complex and can easily be misunderstood. Not only does lack of accessibility make the crisis standards of care plan difficult to follow, but it can also put the public's safety at risk if they misinterpret safety information and follow it improperly. It is important for the language to be clear t to remove literacy barriers. Distributing materials that empower patients and break down the messaging is essential. To make accessibility a success in the finalized crisis standards of care plan, it is important

to hear a patient's perspective to make sure that the messaging presented is understandable for the general public. This cannot be done successfully without public engagement and patient advocates on the SMDAC.

As mentioned in our previous letter, diversity on the advisory committee is vital to the growth of a strong crisis standards of care plan and ensures that discrimination does not take place. Neglecting to include various viewpoints and public comment can result in oversight, and inaccurate assumptions about what is most beneficial to diverse needs of patients. Obtaining a broader perspective on the SMDAC that includes the invaluable patient voice, is essential when creating a strong and reliable crisis standards of care plan for everyone. Furthermore, the language in the draft SOC regarding appointments to the SMDAC reference inclusion of stakeholders that are "community representatives." While we are pleased to see leadership of associations and health care providers on the SMDAC, it is critical that the patient and caregiver perspective is also incorporated into the SMDAC. Therefore, we request that a patient advocate immediately be appointed to the SMDAC. NORD is fortunate to have several strong patient advocates in the state of New Hampshire who we believe would be an excellent fit for this important SMDAC position and would be happy to provide recommendations.

NORD wants to ensure that the crisis standards of care plan support all people of New Hampshire, including the individuals that our organization represents. Please consider appointing a patient representative to the SMDAC so the inclusion of this essential voice can begin immediately. NORD also urges you to finalize these guidelines as soon as possible so the important work of implementing them in a transparent and accountable manner can occur. Thank you for your consideration. If you have any questions or need further information, please contact Annissa Reed, NORD's State Policy Manager for the Eastern Region at AReed@rarediseases.org.

Sincerely,

Annissa Reed

Annissa Reed

State Policy Manager, Eastern U.S.

Krista M. Gilbert

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New Hampshire Volunteer State Ambassador

