CYSTIC FIBROSIS FOUNDATION®

May 8, 2020

Jonathan Ballard MD, MPH, MPhil
Chief Medical Officer
New Hampshire Department of Health and Human Services
129 Pleasant Street
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Electronically sent to: jonathan.ballard@dhhs.nh.gov

Dear Dr. Jonathan Ballard:

On behalf of those living with cystic fibrosis in New Hampshire, we write to comment on the state's document entitled "New Hampshire Crisis Standards of Care Plan."[1] We recognize the monumentally difficult task public health officials face when creating allocation guidelines that are both equitable and actionable during this crisis, and we appreciate that the New Hampshire Department of Health and Human Services has taken steps toward creating clinical guidelines that will aid healthcare providers during the current Coronavirus Disease 2019 (COVID-19) pandemic.

We are encouraged that the state's crisis standards of care plan contains principles stating allocation decisions cannot be based on disability or underlying conditions. However, we are concerned that New Hampshire's plan refers clinicians to the Minnesota Crisis Standards of Care standardized tools. In particular, the mechanical ventilation and external oxygenation allocation tool created by the Minnesota Department of Health uses the presence of underlying health conditions – including cystic fibrosis patients requiring continuous home oxygen use – as a determining factor in deciding which patients receive ventilators and external oxygenation in the event that limited supply requires rationing of care. Such decisions could result in the denial of life-saving care for patients with CF who seek treatment while the plan is active, solely based on their underlying conditions – even though there is no evidence to suggest that people with CF cannot make a full recovery from COVID-19.

While decisions about who receives treatment should never be based on underlying diagnoses, the criteria in Minnesota's tool is also based on an inaccurate understanding of current survival outcomes for the CF patient population and does not factor in the short- and long-term impact of disease-modifying therapy. The outlook has dramatically improved in recent years for patients living with cystic fibrosis, even those with low lung function, thanks to recent advances in care and treatment options. The median survival for patients with CF with an FEV_1 of less than 30% is 6.5 years.[2] We expect that the introduction of new and transformational therapies like Trikafta™, which treats the underlying cause of the disease, will only further improve life expectancy. Moreover, preliminary data from the CF patient registry—which collects data from accredited CF care centers and includes 97 percent of CF patients in the US—shows that there has only been one death among the 25 confirmed cases of COVID-19. This

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[1] https://www.dhhs.nh.gov/documents/nh-csc-plan.pdf
[2] https://www.atsjournals.org/doi/pdf/10.1164/rccm.202004-0999LE

includes four patients with advanced lung disease, defined as those with a FEV_1 less than 40 percent, and three patients post-lung transplantation.

State crisis standards of care guidelines that are transparent and ensure equitable access to scarce resources are an important tool for protecting both care providers and patients in this difficult time, and we appreciate New Hampshire's commitment to ensuring that patients with underlying conditions are not unfairly disadvantaged by allocation schemes. We look forward to working with you as the state continues to revise and develop crisis standards of care clinical guidelines.

Sincerely,

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