



May 5, 2020

Disaster Clinical Advisory Committee
Northwest Healthcare Response Network
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Tukwila, WA 98188

Electronically sent to: info@nwhrn.org

To whom it may concern:

On behalf of those living with cystic fibrosis in Washington State, we write to comment on the document entitled "Scarce Resource Management & Crisis Standards of Care."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 applaud the Washington State Department of Health and the Disaster Clinical Advisory Committee for recognizing the need to update these standards of care to accommodate unique circumstances during the COVID-19 pandemic.

We are encouraged to see that the state has committed to preventing discrimination when allocating scarce resources and the guidelines reiterate that all treatment decisions should be based on individualized assessment. However, we are concerned that the adult critical care triage worksheet, updated April 2020, contains references to people with underlying conditions that could unfairly disadvantage people with CF during the pandemic. Specifically, the worksheet advises providers to consider whether patients have significant underlying diseases predictive of poor short-term survival, including severe chronic lung disease, when determining which patients receive intensive care and which resources are re-allocated. These criteria reflect an outdated understanding of current survival outcomes for the CF patient population.

Life expectancy for patients living with cystic fibrosis has dramatically improved in recent years, even those with low lung function, thanks to recent advances in care and treatment options. In fact, the median survival for patients with CF with an FEV₁ 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 includes four patients with advanced lung disease, defined as those with a FEV₁ less than 40% predicted, and three patients post-lung transplantation.

¹ https://nwhrn.org/wpcontent/uploads/2018/10/Scarce_Resource_Management_and_Crisis_Standards_of_Care_Overview_and_Materials-2020-04-10.pdf

² <https://www.atsjournals.org/doi/pdf/10.1164/rccm.202004-0999LE>

Every patient with CF must be evaluated and triaged for COVID-19 treatment on a case-by-case basis based on their acute clinical presentation, rather than on the presence of an underlying disease. As the state considers future revisions, we encourage the Department of Health and the Disaster Clinical Advisory Committee to avoid references to severe chronic lung disease that may unfairly disadvantage patient access to scarce resources for those with underlying conditions such as cystic fibrosis. Additionally, where feasible, we urge Washington State to create triage plans that leverage available disease-specific experts on site to ensure assessments tied to allocation determinations include the best available objective medical evidence.

Thank you for taking the all-important first step of revising the state's allocation guidelines in light of the COVID-19 pandemic. Plans 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. We look forward to working with you as you continue to revise the crisis standards of care plan for your state.

Sincerely,

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