

Sen. Jacque: Letter to DHS Secretary-designee Andrea Palm

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Secretary-designee Andrea Palm

Department of Health Services

1 West Wilson Street

Madison, Wisconsin 53703

Secretary-designee Palm,

I am writing to ask that you share this letter with the members of the State Disaster Medical Advisory Committee Long-Term Care Subcommittee prior to their meeting on Thursday, April 16.

I am writing on behalf of my constituents because it has recently come to my attention that Wisconsin is one of five states that had policies and guidelines in place that specify that patients with cystic fibrosis should not be considered for a ventilator. Although DHS has now removed such a guidance document from their web page, as your subcommittee meets to discuss an updated policy that would potentially impact patients with cystic fibrosis I ask that you amend and better define the orange section on “severe chronic lung disease”.

Unless modifications are made, this is where triaging by medical providers with little understanding of cystic fibrosis may wrongly categorize cystic fibrosis patients

because CF is deemed a severe chronic lung disease- despite the fact that advances in medicine have made it a manageable disease for most, with ever expanding life expectancy. I understand that the red category in which severe lung disease is noted is specific to transplant ineligible patients and there are medical parameters defining severe chronic lung disease. Furthermore, the orange category criteria severe lung disease is not defined by medical parameters, but the main bullet does denote that this is in regard to transplant eligible patients. Less than 1% of CF patients would technically meet this end stage transplant eligible criteria, however if the guidelines are not written to be more clear and better defined we risk providers with limited understanding of cystic fibrosis wrongly assuming that CF patients have chronic severe lung disease and place them in the orange category even if this is not the case. In addition, I am deeply concerned about the guidance document previously posted by the Wisconsin Hospital Association at the request of DHS because I believe it could lead to potentially deadly discrimination against cystic fibrosis patients with well-managed treatment and lung function near normal parameters that just happen to contract COVID-19.

I believe it is essential to ensure that any medical triage/rationing policy issued by the State specifically recognize that “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. 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.”

The lives of people with disabilities are equally worthy and valuable as those of people without disabilities. People with disabilities must have an equal opportunity to receive life-sustaining treatment. The laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else.

Thank you for your consideration.



Sincerely,

Senator André Jacque