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KIF1A.ORG Rejects Discriminatory Ventilator Allocation Protocols and Calls for Immediate Action

March 29, 2020

The KIF1A.ORG Leadership Team is closely monitoring reports that governments and medical institutions will soon be implementing catastrophic and discriminatory pandemic ventilator allocation protocols, preventing life-saving access to ventilators.

The unthinkable circumstance of pandemic ventilator allocation and prioritization of human life is tragic and should not occur in 2020; however, it is a reality that patient lives will be prioritized and individuals (children and adults) affected by neurological and neuromuscular diseases (who would otherwise have access to ventilators) should not be de-prioritized because of inaccurate clinical guidelines and uninformed exclusion criteria. Many of these exclusion criteria apply to individuals who now lead full lives, have available treatments, cures and emerging access to life-saving therapeutics.

Current guidelines for ventilator allocation could exclude children and adults with neurological disabilities. New York guidelines state that “patients with the smallest probability of mortality with medical intervention, have the lowest level of access to ventilator therapy.”

In Alabama, neurological disorders may exclude patients from ventilator access during emergencies. Of notable concern: “persons with severe mental retardation … may be poor candidates for ventilator support,” and “Children with severe neurological problems may not be appropriate candidates in the pediatric age group.”

In Tennessee, exclusion criteria for hospital admission “during a community-wide public health emergency” includes “Advanced untreatable neuromuscular disease (such as ALS, end-stage MS, spinal muscular atrophy) requiring assistance with activities of daily living...” As we know, these criteria are grossly inaccurate. SMA has approved treatments, and the word “untreatable” does not apply to most neuromuscular diseases today. Treatments are either approved and accessible, or in late-stage clinical trial (where patients technically are being treated, albeit with an investigational therapy).

In Washington, disability advocate organizations filed a complaint against state agencies and organizations for “illegal disability discrimination that is putting the lives of people with disabilities at imminent risk during the COVID-19 pandemic.” For example, triage guidelines released this month instruct healthcare workers to “consider transferring the following patients to out-patient or palliative care,” such as patients with neuromuscular disorders, if “resources are inadequate.”

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Let us be clear: Life-saving care and treatment should NOT be withheld from patients simply because they live with a neurological disorder or disability.

These irresponsible protocols imply that some lives hold more value than others because individuals may live, work, play, grow and contribute to society differently. Different does not mean less. Different does not mean unworthy. With the reality of pandemic and the ethical choices our clinicians will be forced to make, policymakers must ensure these guidelines do not unjustly discriminate on the basis of inaccurate medical information and assumptions of the quality and length of a person's life because he or she lives with a chronic or rare neurological disease.

Our message to rare disease patients and families: continue to be relentless. Take extra precautions to protect your health and safety. Be informed and reject any notion that you or your loved one is not worthy of care. Call for immediate review of ventilator allocation guidelines that will affect your family.

Whether we're battling KIF1A or COVID-19, we will unite as a community and call on our leaders. We will scream from the mountaintops and relentlessly advocate for KAND families around the world, and every family affected by rare diseases.

With Relentless Solidarity,

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