May 20, 2020

The Honorable Alex Azar Secretary U.S. Department of Health and Human Services 200 Independence Avenue S.W. Washington, DC 20201

Roger Severino Director Office for Civil Rights U.S. Department of Health and Human Services 200 Independence Avenue S.W. Washington, DC 20201

Dear Secretary Azar and Director Severino:

The undersigned organizations represent millions of patients who may be at increased risk of complications related to COVID-19, including those with cancer, cystic fibrosis, epilepsy, serious lung diseases like asthma and COPD, kidney disease, liver disease, and other conditions. We urge the Department of Health and Human Service's (HHS's) Office for Civil Rights (OCR) to issue additional guidance to make clear that state emergency triage guidance that would limit or restrict access to life-saving care for certain patients with underlying conditions due to the COVID-19 pandemic violates federal antidiscrimination laws.

Our organizations applaud the actions that many states have taken to flatten the curve and acquire more life-saving ventilators and other critical equipment. However, if we reach a point where emergency triage protocols must be activated, states, hospitals, and health systems need strong, clear guidance from OCR.

We appreciate the joint HHS/OCR bulletin issued on March 28, which says "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 or age. 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."¹

Notwithstanding this bulletin, a number of states are developing COVID-19 action plans and toolkits that provide guidance to medical professionals on how to create emergency triage portfolios with regard to scarce health care resources. We have found that some of these guidances use pre-existing diagnoses to determine who receives care, discriminating against the patients we represent with underlying health conditions.

As states develop these action plans, we urge HHS and OCR to continue to make clear that any plan for allocating scarce medical resources during the present emergency, or any future one, ensures that *all* patients—regardless of underlying conditions—are equally eligible for treatment based on their current clinical presentation.

¹ HHS Office for Civil Rights in Action. BULLETIN: Civil Rights, HIPAA, and Coronavirus Disease 2019 (COVID-19). Mar. 28, 2020. Available at <u>https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf</u>.

Guidance should include the following:

- Decisions about who receives care should be based on the patient's likelihood of responding to a treatment.
- All persons should be qualified to receive lifesaving care, regardless of the presence of an underlying condition or advanced age.
- States should be transparent in their guidance to hospitals and health systems to ensure public accountability.

Our organizations thank you again for the OCR guidance from March 28 and encourage additional guidance to create more clarity for states and health systems. Our organizations are happy to provide a patient perspective on this important issue.

For more information or to discuss further, please direct your staff to contact Stephanie Krenrich at the American Cancer Society Cancer Action Network at <u>Stephanie.Krenrich@cancer.org</u>.

Sincerely,

Alliance for Aging Research Alpha-1 Foundation American Cancer Society Cancer Action Network American Kidney Fund American Lung Association Arthritis Foundation Association of American Cancer Institutes **Cancer Support Community** CancerCare Children's Cancer Cause Chronic Disease Coalition COPD Foundation **Cystic Fibrosis Foundation** Debbie's Dream Foundation **Epilepsy Foundation Family Voices Fight Colorectal Cancer** FORCE: Facing Our Risk of Cancer Empowered **Global Liver Institute** GO2 Foundation for Lung Cancer Harm Reduction Coalition Hemophilia Federation of America International Myeloma Foundation KidneyCAN LUNGevity Foundation

Mattie Miracle Cancer Foundation Melanoma Research Foundation Mended Hearts & Mended Little Hearts Muscular Dystrophy Association National Alliance on Mental Illness National Cancer Registrars Association National Coalition for Cancer Survivorship National Health Council National Hemophilia Foundation National Kidney Foundation National Organization for Rare Disorders National Patient Advocate Foundation **Oncology Nursing Society** Prevent Cancer Foundation Pulmonary Hypertension Association Society for Immunotherapy of Cancer Susan G. Komen The AIDS Institute **Triage Cancer** WomenHeart: The National Coalition for Women with Heart Disease ZERO - The End of Prostate Cancer