

UNITED STATES DISTRICT COURT  
EASTERN DISTRICT OF NEW YORK

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NOT DEAD YET, NMD UNITED,  
DISABILITY RIGHTS NEW YORK,  
MICHELLE BROSE, MIKE VOLKMAN,  
JESSICA TAMBOR, and PERI  
FINKELSTEIN, individually and on behalf of  
a class of all others similarly situated,

CIVIL CASE NO: 1:20-cv-4819

**CLASS ACTION COMPLAINT**

Plaintiffs,

-against-

ANDREW CUOMO, Governor of the State  
of New York, in his official capacity, and  
HOWARD A. ZUCKER, Commissioner of  
the New York State Department of Health, in  
his official capacity.

Defendants.

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**PRELIMINARY STATEMENT**

1. Plaintiffs, chronic ventilator users who reside in New York State and organizations that represent them, bring this action on behalf of themselves and all others similarly situated challenging the New York State Department of Health’s Ventilator Allocation Guidelines (“Guidelines”). The Guidelines allow hospitals to reallocate the personal ventilators of people who seek acute medical care in a hospital during a time of triage to others deemed more likely to survive based on a mechanical scoring system.

2. The Guidelines deprive people with disabilities of a nondiscriminatory emergency preparedness program and risk placing chronic ventilator users in potentially life-threatening situations in violation of the Americans with Disabilities Act (“ADA”), 42 U.S.C. § 12101, *et*

*seq.*, Section 504 of the Rehabilitation Act of 1973 (“Section 504”), 29 U.S.C. § 794, *et seq.*, and the Affordable Care Act (“ACA”) 42 U.S.C. § 18116, *et seq.*

3. In November 2015, the New York State Task Force on Life and the Law (“Task Force”) and the New York State Department of Health (“NY DOH”) published the Guidelines to address how to “ethically allocate limited resources (i.e. ventilators) during a severe influenza pandemic while saving the most lives.” New York State Task Force on Life and the Law & New York State Department of Health, *Ventilator Allocation Guidelines* at “Letter from the Commissioner of Health” (2015), available at [https://www.health.ny.gov/regulations/task\\_force/reports\\_publications/docs/ventilator\\_guidelines.pdf](https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf).

4. The NY DOH stated that the Guidelines “provide an ethical, clinical, and legal framework to assist health care providers and the general public in the event of a severe influenza pandemic.” *Id.*

5. Originally created in anticipation of a flu pandemic, the Guidelines gained prominence in March 2020 when the COVID-19 pandemic hit New York with unprecedented force.

6. During a two-week period at the peak of the pandemic in April 2020, more than seven hundred New York State residents died *per day* from COVID-19.

7. Ventilators quickly became key to treating COVID-19, which can cause severe respiratory distress in impacted individuals.

8. As New York hospitals admitted hundreds of patients seeking treatment for COVID-19, New York State took steps to address anticipated ventilator shortages, including borrowing ventilators from other states and from nursing and rehabilitation facilities.

9. The Guidelines created wide-spread fear among chronic ventilator users because the Guidelines permit hospitals to requisition patients' personal ventilators and reallocate them to others deemed more likely to survive.

10. Chronic ventilator users, including the Plaintiffs, saw articles and social media posts shared among their friends, classmates, and community members about the Guidelines and the risk of having their personal ventilators taken away if they sought acute medical care in a hospital.

11. Plaintiffs and other chronic ventilator users reported that they would not seek acute medical care during the pandemic for fear of being forcibly extubated, which would lead to their deaths.

12. As of the filing of this complaint, Governor Cuomo has not issued a statement that chronic ventilator users' personal ventilators will not be reallocated upon entry into an acute medical care facility.

13. As the COVID-19 pandemic continues, Plaintiffs fear losing their ventilators, and ultimately their lives, should they need to seek acute medical care at a hospital during a time of triage when ventilators are in short supply.

14. Plaintiffs and the proposed Class seek prospective injunctive relief ordering the Defendants to amend the Guidelines to ensure that chronic ventilator users will not have their personal ventilators reallocated to other individuals, especially without another ventilator readily available for their use.

### **JURISDICTION**

15. Plaintiffs bring federal claims under Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12101, *et seq.*, Section 504 of the Rehabilitation Act of 1973

(“Section 504”), 29 U.S.C. § 794, *et seq.*, and Section 1557 of the Affordable Care Act (“ACA”), 42 U.S.C. § 18116, *et seq.*

16. This Court has subject matter jurisdiction over this action pursuant to 28 U.S.C. §§ 1331 and 1343.

17. Declaratory and injunctive relief are authorized by 28 U.S.C. §§ 2201, 2202.

18. Venue is appropriate in this District pursuant to 28 U.S.C. § 1391(b)(2) as a number of the events and omissions complained of occurred in this District, and Plaintiffs Brose, Finkelstein, and Tambor reside within this District.

### **PARTIES**

19. Plaintiff Michelle Brose is a chronic ventilator user who resides in Staten Island, New York.

20. Plaintiff Mike Volkman is a chronic ventilator user who resides in Albany, New York.

21. Plaintiff Peri Finkelstein is a chronic ventilator user who resides in West Hempstead, New York.

22. Plaintiff Jessica Tambor is a chronic ventilator user who resides in Queens, New York.

23. Plaintiff Not Dead Yet is a national grassroots disability rights group and not-for-profit corporation based in Rochester, New York.

24. Plaintiff NMD United is a peer-led non-profit organization serving adults living with neuromuscular disabilities.

25. Plaintiff Disability Advocates, Inc. is an independent non-profit corporation organized under the laws of the State of New York. Disability Advocates, Inc. is authorized to conduct business under the name Disability Rights New York (DRNY).

26. DRNY is a Protection and Advocacy system (P&A), as that term is defined under the Developmental Disabilities Assistance and Bill of Rights Act (“DD Act”), 42 U.S.C. § 15041, et seq., the Protection and Advocacy for Individuals with Mental Illness Act of 1986 (“PAIMI Act”), 42 U.S.C. § 10801, et seq., and the Protection and Advocacy of Individual Rights Act (“PAIR Act”), 29 U.S.C. § 794e, et seq., with offices in the State of New York located at: 25 Chapel Street, Suite 1005, Brooklyn, NY 11201; 725 Broadway, Suite 450, Albany, NY 12208; and 44 Exchange Blvd., Suite 110, Rochester, NY 14614.

27. As New York State’s Protection & Advocacy system, DRNY is specifically authorized to pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of individuals with disabilities. 42 U.S.C. § 15043(a)(2)(A)(i); N.Y. Exec. Law § 558(b).

28. Pursuant to the authority vested in it by Congress to file claims of abuse, neglect, and rights violations on behalf of individuals with disabilities, DRNY brings claims on behalf of individuals with disabilities, including the individuals named herein.

29. Defendant Andrew Cuomo is the current Governor of the State of New York. He is sued in his official capacity. He is responsible for supervising and monitoring the programs and activities of the NY DOH, as an agency of New York State, and has ultimate authority over the content of the Ventilator Allocation Guidelines.

30. Defendant Howard A. Zucker is the current Commissioner of the New York State Department of Health. He is sued in his official capacity. Commissioner Zucker is responsible

for the operation and management of the NY DOH, including the development, monitoring, and implementation of the Ventilator Allocation Guidelines.

## **STATEMENT OF FACTS**

### **New York State Ventilator Allocation Guidelines**

31. The Guidelines state that the NY DOH is “empowered to issue voluntary, non-binding guidelines for health care workers and facilities; such guidelines are readily implemented and provide hospitals with an ethical and clinical framework for decision-making.” *Guidelines* at 8.

32. The New York State Administrative Procedure Act (“SAPA”) defines a “guidance document” as “any guideline, memorandum or similar document prepared by an agency that provides general information or guidance to assist regulated parties in complying with any statute, rule or other legal requirement.” N.Y. A.P.A. Law § 102(14).

33. The Guidelines are a “guidance document” within the meaning of the NY SAPA.

34. The Guidelines acknowledge that hospitals will likely follow the Guidelines even if they are non-binding, stating: “Hospitals have expressed a preference for State guidance over drafting their own policies.” *Guidelines* at 206.

35. The Task Force also explicitly encouraged adherence to the Guidelines: “Although the Guidelines are voluntary, the Task Force strongly recommends that they be adopted and followed by all health care providers and entities in a pandemic.” *Id.* at 206.

36. New York’s largest healthcare provider, Northwell Health, which operates twenty-three hospitals in New York State, stated publicly that it would follow the Guidelines if it ran out of ventilators. *See* Tyler Foggatt, Who Gets a Ventilator?, *The New Yorker*, April 11, 2020, <https://www.newyorker.com/magazine/2020/04/20/who-gets-a-ventilator>

<https://www.newyorker.com/magazine/2020/04/20/who-gets-a-ventilator> (last visited Oct. 6, 2020).

### **Ventilator Allocation Protocol**

37. The Guidelines set forth a process for an acute medical facility to follow to determine who will receive a ventilator when there is a shortage of ventilators in the facility. *Guidelines* at 3.

38. Under the Guidelines, a patient's physician does not determine whether the patient receives or continues to receive a ventilator, instead, a triage officer or triage committee makes the decision of whether a patient receives or gets to keep a ventilator. *Id.* at 5.

39. A triage officer or triage committee does not have any direct contact with the patient. "Instead, a triage officer or triage committee examines the data provided by the attending physician and makes the determination about a patient's level of access to a ventilator." *Id.*

40. The triage officer or triage community only uses clinical factors to evaluate a patient's likelihood of survival and to determine the patient's access to ventilator therapy. *Id.*

41. The Guidelines state that, "This role sequestration allows the clinical ventilator allocation protocol to operate smoothly. The decision regarding whether to use either a triage officer or committee is left to each acute care facility (i.e., hospital) because available resources will differ at each site." *Id.*

42. The Guidelines use a multi-step process with a Sequential Organ Failure Assessment (SOFA) score to determine which patients will have access to a ventilator during a time of triage.

43. A SOFA score is a number used to track a person's status during an intensive care stay that adds points based on clinical measures of the function of six key organs and systems: lungs, liver, brain, kidneys, blood clotting, and blood pressure. *Id.* at 14.

44. Chronic ventilator users automatically have reduced SOFA scores because their disabilities significantly impair the functioning of key organ systems such as the lungs, among others.

45. The Guidelines permit hospitals to take chronic ventilator users' personal ventilators upon their arrival into a hospital and place them into the general ventilator allocation pool for distribution to those with higher SOFA scores. *Id.* at 40.

46. The Guidelines acknowledge that the policy "may place ventilator-dependent individuals in a difficult position of choosing between life-sustaining ventilation and urgent medical care." *Id.* at 41.

47. The Guidelines also recognize that the triage policy "may deter chronic care patients from going to an acute care facility for fear of losing access to their ventilator" and that "if the ventilator is removed from a person known to depend upon it, s/he will not survive, regardless of the reason requiring hospitalization." *Id.* at 41-42.

48. The Guidelines further conclude that "[r]esource limitations may require that ventilation therapy be withheld or withdrawn from some persons without obtaining prior first person (or proxy) consent." *Id.* at 206-07.

### **Plaintiff Specific Facts**

#### ***Michelle Brose***

49. Plaintiff Michelle Brose is a 45-year-old chronic ventilator user and a resident of Staten Island, New York.



50. Ms. Brose is studying biology at Columbia University. Although she usually lives on campus at Columbia, she currently attends classes remotely from her family home in Staten Island due to the ongoing COVID-19 pandemic.

51. Ms. Brose is a member of organizational plaintiff NMD United.

52. Ms. Brose is a qualified individual with a disability within the meaning of Title II of the ADA, Section 504, and Section 1557 of the ACA. She has Charcot Marie-Tooth disease, which causes motor and sensory neuropathy of the peripheral nervous system characterized by progressive loss of muscle tissue and touch sensation across various parts of the body, and which affects her ability to breathe on her own.

53. Ms. Brose has used a ventilator since 1994. She is completely ventilator dependent and uses a ventilator 24 hours per day because she cannot breathe on her own.

54. Ms. Brose uses one ventilator during the day and the other ventilator at night.

55. Ms. Brose knows of the provision in the New York Ventilator Allocation Guidelines that permits hospitals to reallocate personal ventilators during triage scenarios.

56. Ms. Brose first learned of the Guidelines from her biology classmates who were joking about the pandemic and ventilator shortages in an online forum. Ms. Brose clicked on the link they shared and discovered with horror that the Guidelines specifically contemplated taking her personal ventilator from her.

57. Ms. Brose understood the Guidelines to mean that she could not go to a hospital if she tested positive for the coronavirus for fear of losing access to her life-sustaining personal ventilator.

58. Prior to the COVID-19 pandemic, Ms. Brose had 24-hour personal care attendants. However, once the pandemic began, she no longer felt safe risking aides coming into

her home due to her greater susceptibility to the virus. As a result, her mother and sister have been tending to her care since the beginning of the pandemic.

59. Ms. Brose knows that during COVID-19, hospital policies have limited family members' ability to stay with patients, and she fears that in a triage scenario with nobody there to advocate for her, she could have her ventilator taken away from her pursuant to the Guidelines.

60. As a New York State resident and chronic ventilator user to whom the Guidelines would apply, Ms. Brose fears having to make the impossible choice between foregoing needed medical care or going to the hospital where, due to the lack of a nondiscriminatory emergency preparedness plan, her personal ventilator could be taken away, resulting in her inability to breathe and imminent death.

***Mike Volkman***

61. Plaintiff Mike Volkman is a 55-year-old chronic ventilator user and a resident of Albany, New York.

62. Mr. Volkman serves on the Board of Directors of organizational plaintiff Not Dead Yet.

63. Mr. Volkman is a qualified individual with a disability within the meaning of Title II of the ADA, Section 504, and Section 1557 of the ACA. He has spinal muscular atrophy (SMA), a progressive condition characterized by weakness and atrophy of skeletal muscles, which affects his ability to breathe on his own.

64. Mr. Volkman has used a ventilator since 2015 and uses it 24 hours per day.

65. Mr. Volkman has two ventilators, a stationary ventilator used at night and a portable ventilator that he keeps on the back of his wheelchair.

66. Mr. Volkman lives independently in his community and receives 24-hour care from home health aides who assist him with daily tasks.

67. Mr. Volkman has been admitted to the hospital nine times since he started using his ventilator.

68. Mr. Volkman considers hospital stays to be extremely dangerous for him. He does not have a family member or other person available to stay with him at the hospital and is also without his home health aides who are trained in the specifics of his medical conditions.

69. As a result, he fears that he will encounter circumstances in which he will not be able to advocate for himself and medical decisions will be made on his behalf without his input.

70. During previous hospital admissions both prior to and during the COVID-19 pandemic, in accordance with hospital policies, the hospital has removed Mr. Volkman from his personal ventilator and placed him on a hospital ventilator despite his preference to remain on his own personal ventilator.

71. Mr. Volkman knows of the provision in the Guidelines that permits hospitals to reallocate personal ventilators during triage scenarios.

72. He fears that, especially in the midst of this ongoing global pandemic, where the number of patients presenting with respiratory symptoms is increasing and the demand for ventilators could potentially outpace the supply, if he as a chronic ventilator user goes to a hospital, his personal ventilator could be considered a hot “commodity” for someone else’s benefit and he will have to compete for survival.

73. As a New York State resident and chronic ventilator user to whom the Guidelines would apply, Mr. Volkman fears having to make the impossible choice between foregoing needed medical care or going to the hospital where, due to the lack of a nondiscriminatory

emergency preparedness plan, his personal ventilator could be taken away, resulting in his inability to breathe and eventual death.

***Jessica Tambor***

74. Plaintiff Jessica Tambor is a 34-year-old chronic ventilator user and a resident of Queens, New York.

75. Ms. Tambor works at the Bronx Independent Living Services as an Independent Living Specialist.

76. Ms. Tambor is a qualified individual with a disability within the meaning of Title II of the ADA, Section 504, and Section 1557 of the ACA. She sustained a spinal cord injury at birth, which affects her ability to breathe on her own.

77. Ms. Tambor has used a ventilator throughout her entire life. She uses the ventilator approximately 12 hours per day, throughout the night and occasionally during the day.

78. She lives with her family in Queens and her parents assist her with daily tasks.

79. Ms. Tambor knows of the provision in the Guidelines that permits hospitals to reallocate personal ventilators during triage scenarios.

80. She learned about the Guidelines on Facebook where she saw friends and other ventilator users posting about the potential need for rationing of ventilators and the possibility that people's personal ventilators could be taken away and given to other patients.

81. As a New York State resident and a chronic ventilator user to whom the Guidelines would apply, Ms. Tambor fears having to make the impossible choice between foregoing needed medical care or going to the hospital where, due to the lack of a nondiscriminatory emergency preparedness plan, her personal ventilator could be taken away, resulting in her inability to breathe and eventual death.

*Peri Finkelstein*

82. Plaintiff Peri Finkelstein is a 20-year-old chronic ventilator user and resident of West Hempstead, New York.

83. Ms. Finkelstein is studying marketing at Adelphi University.

84. Ms. Finkelstein is a qualified individual with a disability within the meaning of Title II of the ADA, Section 504, and Section 1557 of the ACA. She has a rare form of Muscular Dystrophy and has used a ventilator since the age of two.

85. Ms. Finkelstein is completely ventilator dependent and uses a ventilator 24 hours per day because she cannot breathe on her own. She has two ventilators that she uses at different times throughout the day and night.

86. Ms. Finkelstein lives with her parents, and they assist her with daily tasks.

87. Ms. Finkelstein has spent a significant amount of time in the hospital. Each time, her parents accompanied her at all times and advocated for her needs.

88. Ms. Finkelstein knows of the provision in the New York Ventilator Allocation Guidelines that permits hospitals to reallocate personal ventilators during triage scenarios.

89. Ms. Finkelstein first learned about this provision of the Guidelines on the Internet in March of 2020. She discovered that the Guidelines place people with disabilities at risk and that if she had to go to the hospital, her ventilator could be taken away.

90. After hearing about the Guidelines, Ms. Finkelstein did not leave her house for months.

91. She and her mother also feared having to go to the hospital during this time.

92. Additionally, Ms. Finkelstein will turn 21 years old this year. This impending milestone has compounded her fears about the Guidelines.

93. As a legal adult, Ms. Finkelstein will no longer qualify for services from the pediatric division of the hospital, which means that the hospital may prevent her parents from staying with her at all times and advocating for her needs.

94. Ms. Finkelstein would have great difficulty advocating for herself while hospitalized, particularly at night, because the night-time configuration of her ventilator inhibits her ability to speak.

95. As a New York State resident and a chronic ventilator user to whom the Guidelines would apply, Ms. Finkelstein fears that her ventilator could be taken away from her and reallocated in a triage scenario.

96. Due to the lack of a nondiscriminatory emergency preparedness plan, she would have to make the impossible decision of whether to stay home and not access medical care, or to go to the hospital, where her personal ventilator would likely be taken away, resulting in her inability to breathe and eventual death.

***Not Dead Yet***

97. Plaintiff Not Dead Yet is a not-for-profit corporation and grassroots disability rights group that opposes legalization of assisted suicide, and euthanasia as deadly forms of discrimination, and the non-voluntary withdrawal or withholding of life-sustaining medical treatment, including but not limited to, futility policies involving health care provider decisions to withhold or withdraw life-sustaining medical treatment.

98. Not Dead Yet provides information and referral services, including legal referrals, to individuals who face discrimination in the provision of life-sustaining medical care as well as to people who are being denied lifesaving medical treatment.

99. Not Dead Yet's constituents are qualified individuals with disabilities within the meaning of Title II of the ADA, Section 504, and Section 1557 of the ACA.

100. Several of Not Dead Yet's constituents are chronic ventilator users who reside in New York State, including its President and CEO, Rochester resident Diane Coleman.

101. Staff and board members of Not Dead Yet regularly give presentations to disability rights groups, people with disabilities, and their families, on a variety of topics related to disability discrimination and the provision of healthcare services, including assisted suicide, the withholding of medical treatment, the effects of end-of-life policies on people with disabilities, and health care disparities based on race.

102. Not Dead Yet has known about the Guidelines since shortly after their publication in November 2015.

103. At that time, a Not Dead Yet staff member responsible for tracking developments in healthcare reviewed the Guidelines and raised concerns to the rest of the staff about language in the Guidelines that allowed hospitals to reallocate personal ventilators and the life-threatening consequences that this would create for the constituents Not Dead Yet serves.

104. As COVID-19 spread across the country and New York State, in particular, with discussion of possible ventilator shortages, Not Dead Yet constituents expressed concerns about having their ventilators taken away if they needed to go to the hospital.

105. In response to these concerns, the organization has expended significant time and resources to inform and advocate for its constituents with respect to the Guidelines.

106. Staff of Not Dead Yet has given a number of presentations about disability discrimination and triage policies, including ventilator reallocation, during COVID-19.

107. In March and April of 2020, Diane Coleman wrote posts on the Not Dead Yet Blog about the ventilator reallocation provision of the Guidelines.

108. Due to the lack of a nondiscriminatory emergency preparedness plan, Not Dead Yet's New York constituents who rely on personal ventilators would face the impossible choice between foregoing needed medical care or going to the hospital where their personal ventilators could be taken away, resulting in an inability or reduced ability to breathe and leading to respiratory failure and death.

***NMD United***

109. Plaintiff NMD United is a non-profit organization serving adults living with neuromuscular disabilities. NMD United is a peer-led organization that works to foster interactions and provide informational resources to increase self-direction while promoting independence.

110. NMD United's members are qualified individuals with disabilities within the meaning of Title II of the ADA, Section 504, and Section 1557 of the ACA.

111. Several of NMD United's members are chronic ventilator users who reside in New York State.

112. NMD United supports its membership through a variety of programs. These programs include a free series called NMD United Virtual University for adults with neuromuscular disabilities to discuss important issues relevant to their lives and independence and a grant program that helps adults living with neuromuscular disabilities by providing funding for medical supplies, vehicle maintenance and repair, assistive technology, and personal care attendant advertisement fees. NMD United has given out more than 100 grants to date.



113. NMD United also has an active Facebook group, which it uses to communicate with members and other people it serves.

114. NMD United frequently solicits the opinions and concerns of its members and constituents through surveys and polls. Interaction with members is essential to ensuring that NMD United fulfills its mission.

115. In March of 2020, NMD United published a COVID-19 Guide for adults living with neuromuscular disabilities. This guide provided members with information about how to reduce and prevent the spread of COVID-19, as well as life-management strategies for people with neuromuscular disabilities living through the pandemic.

116. Additionally, from March through May of 2020, NMD United conducted an anonymous online survey of its members' primary concerns and advocacy priorities in light of COVID-19. Responders identified themselves according to their zip codes.

117. Several responders located within zip codes of New York State identified themselves as personal ventilator users.

118. In response to a survey question asking what supplies, resources, and equipment responders might need, several responders with zip codes within New York State asked "Do I need to be afraid that my ventilator or other necessary equipment will be taken away?" They also expressed fears about having to seek medical attention at a hospital.

119. Due to the lack of a nondiscriminatory emergency preparedness plan, NMD United's New York members who rely on personal ventilators would face the impossible choice between foregoing needed medical care or going to the hospital where their personal ventilator could be taken away, resulting in their inability to breathe and eventual death.

*Disability Rights New York*

120. DRNY is the Protection and Advocacy Agency for New York State.

121. As early as March 2020, DRNY began to receive calls and inquiries from chronic ventilator users who expressed concerns that they could lose access to their personal ventilator should they seek acute healthcare during the COVID-19 pandemic.

122. In response to complaints from chronic ventilator users stating that they feared seeking acute medical care at a hospital during COVID-19 because of the Guidelines, on March 26, 2020, DRNY sent a letter to Andrew Cuomo, Governor of the State of New York.

123. The DRNY letter requested that NY DOH issue clear guidance regarding the potential for discrimination against people with disabilities seeking medical care during the COVID-19 pandemic, including an unequivocal statement that a chronic ventilator user would never be extubated without another ventilator readily available for their use.

124. As of the commencement of this action, DRNY has received no response to this letter.

125. On April 7, 2020, DRNY filed a complaint of discrimination with the Office for Civil Rights at the U.S. Department of Health and Human Services.

126. Conciliation efforts associated with this complaint have failed, and as of the commencement of this action, the complaint remains pending.

**CLASS ACTION ALLEGATIONS**

127. Individually named Plaintiffs bring this action on behalf of themselves and all other similarly situated, pursuant to Fed. R. Civ. P. 23 (a) and 23(b)(2).

128. Plaintiffs Brose, Volkman, Tambor, and Finkelstein seek certification of a class defined as:

All chronic ventilator users who are or will be subjected to the New York State Department of Health Ventilator Allocation Guidelines.

129. The proposed class is so numerous that joinder of all members is impracticable.

130. Upon information and belief, the class consists of at least 40 members.

131. All members of the proposed class share common issues of law and fact with respect to the Defendants' obligation to prohibit the reallocation of the personal ventilators of chronic ventilator users to other individuals. Common questions include whether subjecting chronic ventilator users who seek acute healthcare in New York State to the Guidelines constitutes discrimination in violation of Title II of the ADA, Section 504, and Section 1557 of the ACA.

132. The Named Plaintiffs' claims are typical of the claims of the proposed Plaintiff Class. Each Named Plaintiff and all members of the proposed class have applied for, are chronic ventilator users who are or will be subjected to the New York State Department of Health Ventilator Allocation Guidelines.

133. The Named Plaintiffs have all experienced harm as a result of the Defendants' failure or refusal to allow them access to participate in or benefit from a nondiscriminatory emergency preparedness plan.

134. Similarly, all proposed class members, as chronic ventilator users who are or will be subjected to the New York State Department of Health Ventilator Allocation Guidelines have or will experience harm with regard to the deprivation of participation in or the lack of a benefit from programs and services as a result of Defendants' systemic failure or refusal to provide them with a nondiscriminatory emergency preparedness system. The named individual Plaintiffs will fairly and adequately protect the interests of the proposed Class.

135. Plaintiffs have a personal and clearly defined interest in vindicating their rights as well as the rights of the Class in order to obtain prospective injunctive relief prohibiting the reallocation of the personal ventilators of chronic ventilator users.

136. Plaintiffs seek relief that will benefit the entire Class.

137. Plaintiffs' counsel, attorneys at the National Center for Law and Economic Justice (NCLEJ) and Disability Rights New York (DRNY) are attorneys experienced in federal class action litigation involving claims of noncompliance with the ADA, Section 504, and the ACA.

138. Prosecution of separate actions by individual Class members would create a risk of inconsistent or varying adjudication with respect to individual Class members, which would establish incompatible standards of conduct for the party opposing the Class, could be dispositive of the interests of the other Class members, or could substantially impair or impede their ability to protect their interests.

139. Plaintiffs' claims satisfy the requirements of Rule 23(b)(2) of the Federal Rules of Civil Procedure, because Defendant has acted on grounds generally applicable to the named Plaintiffs and each absent member of the proposed class, thereby making final adjudicative and declaratory relief appropriate with respect to the proposed Class as a whole.

**FIRST CLAIM FOR RELIEF**  
**TITLE II OF THE AMERICANS WITH DISABILITIES ACT**  
**42 U.S.C. § 12101, et seq.**

140. Plaintiffs incorporate by reference each and every allegation contained in the foregoing paragraphs as if specifically alleged herein.

141. Congress enacted the ADA "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." 42 U.S.C. §

12101(b)(1). Congress specifically found, inter alia, that “discrimination against individuals with disabilities persists in such critical areas as . . . access to public services.” *Id.* § 12101(a)(3).

142. Title II of the ADA states, in pertinent part:

[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or subjected to discrimination by any such entity.

42 U.S.C. § 12132.

143. A “public entity” includes state and local governments, their agencies, and their instrumentalities. 42 U.S.C. § 12131(1).

144. NY DOH is a “public entity” within the meaning of Title II of the ADA.

145. As mandated by Congress, 42 U.S.C. § 12134, the U.S. Attorney General, through the U.S. Department of Justice (“DOJ”) has promulgated regulations that flesh out and implement the specific requirements of Title II of the ADA applicable to all services, programs, and activities provided or made available by public entities. 28 C.F.R. §§ 35.101, 35.102.

146. The Guidance is a “service[], program[], or activit[y]” of the NY DOH. 28 C.F.R. § 35.130.

147. The term “disability” includes physical and mental impairments that substantially limit one or more major life activities. 42 U.S.C. § 12102(2).

148. A “qualified individual with a disability” is a person “who, with or without reasonable modification to rules, policies or practices . . . meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.” 42 U.S.C. § 12131(2).

149. The individual named Plaintiffs, members of the proposed class, and members of organizational Plaintiffs Not Dead Yet and NMD United who are chronic ventilator users who

have sought or will seek acute medical care in New York State are qualified individuals with a disability, as defined by the ADA.

150. NY DOH's Guidelines violate Title II of the ADA and its implementing regulations by authorizing or failing to forbid actions that:

a. Deny a qualified individual with a disability the benefits of the services, programs, or activities of a public entity because of the individual's disability. 42 U.S.C. § 12132.

b. "Aid or perpetuate discrimination against a qualified individual with a disability by providing significant assistance to an agency, organization, or person that discriminates on the basis of disability in providing any aid, benefit, or service to beneficiaries of the public entity's program." 28 C.F.R. § 35.130(b)(1)(v).

c. "[L]imit a qualified individual with a disability in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving the aid, benefit, or service." 28 C.F.R. § 35.130(b)(1)(vii).

d. "[D]eny a qualified individual with a disability the opportunity to participate in services, programs, or activities that are not separate or different, despite the existence of permissibly separate or different programs or activities." 28 C.F.R. § 35.130(b)(2).

e. "Directly or through contractual or other arrangements, utilize criteria or other methods of administration: (i) That have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability; (ii) That have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the public entity's program with respect to individuals with disabilities; or (iii) That perpetuate the discrimination

of another public entity if both public entities are subject to common administrative control or are agencies of the same State.” 28 C.F.R. § 35.130(b)(3).

f. Fail to “make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.” 28 C.F.R. 35.130(b)(7).

g. “[I]mpose or apply eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.” 28 C.F.R. 35.130(b)(8).

151. As a result of NY DOH’s acts and omissions, chronic ventilator users seeking acute medical care in New York State have and will continue to be deprived of a nondiscriminatory emergency preparedness plan, thereby denying them equal access to the benefits of the services, programs and activities of a healthcare system subject to the NY DOH Guidelines.

**SECOND CLAIM FOR RELIEF**  
**SECTION 504 OF THE REHABILITATION ACT OF 1973**  
**29 U.S.C. § 794**

152. Plaintiffs incorporate by reference each and every allegation contained in the foregoing paragraphs as if specifically alleged herein.

153. Section 504 of the Rehabilitation Act provides, in pertinent part that “[n]o otherwise qualified individual with a disability in the United States... shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be

subjected to discrimination under any program or activity receiving Federal financial assistance.”  
29 U.S.C. § 794(a).

154. NY DOH was, at all times relevant to this action, and is currently a recipient of federal financial assistance within the meaning of Section 504.

155. NY DOH provided and provides a “program or activity” where “program or activity” is described as “all operations of a department, agency, special purpose district or other instrumentality of a State or of a local government.” 29. U.S. C. § 794(b)(1)(A).

156. The Guidelines are a “program or activity” of the NY DOH within the meaning of Section 504.

157. A disability is defined as “a physical or mental impairment that substantially limits one or more major life activities of such individual.” 29 U.S.C. § 705(9)(B) (citing 42 U.S.C. § 12102(1)(A)).

158. Chronic ventilator users who seek acute medical care in New York State are qualified individuals under Section 504.

159. NY DOH’s Guideline violate Section 504 by authorizing, or failing to forbid, actions that:

a. Exclude from participation in, deny the benefits of, or otherwise subject individuals to discrimination on the basis of disability. 29 U.S.C. § 794(a); 45 C.F.R. §§ 84.4(a), 84.52(a)(1); 28 C.F.R. § 41.51(a).

b. Deny qualified persons with a disability the opportunity to participate in or benefit from the aid, benefit, or service. 45 C.F.R. § 84.4(b)(1)(i); 28 C.F.R. § 41.51(b)(1)(i).



c. Afford qualified persons with a disability an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded to others. 45 C.F.R. §§ 84.4(b)(1)(ii), 84.52(a)(2); 28 C.F.R. § 41.51(b)(1)(ii).

d. Limit individuals with a disability in the enjoyment of rights, privileges, advantages and opportunities enjoyed by others receiving an aid, benefit, or service. 45 C.F.R. §§ 84.4(b)(1)(vii), 84.52(a)(4); 28 C.F.R. § 41.51(b)(1)(vii).

e. Use criteria or methods of administration that have the effect of subjecting qualified persons to discrimination on the basis of disability, or that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of a program or activity with respect to persons with disabilities. 45 C.F.R. §§ 84.4(b)(4); 28 C.F.R. § 41.51(b)(3).

160. As a result of NY DOH's acts and omissions, individuals with disabilities seeking acute medical care in New York State have and will continue to be excluded from participation in, denied the benefits of, and subjected to discrimination from a healthcare system subject to the NY DOH Guidelines.

**THIRD CLAIM FOR RELIEF**  
**SECTION 1557 OF THE AFFORDABLE CARE ACT**  
**42 U.S.C. § 18116**

161. Plaintiffs incorporate by reference each and every allegation contained in the foregoing paragraphs as if specifically alleged herein.

162. Section 1557 of the Affordable Care Act (ACA) states, in relevant part:

Except as otherwise provided for in this title (or an amendment made by this title), an individual shall not, on the ground prohibited under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), title IX of the Education Amendments of 1972 (20 U.S.C. 1681 et seq.), the Age Discrimination Act of 1975 (42 U.S.C. 6101 et seq.), or section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any

part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under this title (or amendments). The enforcement mechanisms provided for and available under such title VI, title IX, section 504, or such Age Discrimination Act shall apply for purposes of violations of this subsection.

42 U.S.C. § 18116 (a).

163. The United States Department of Health and Human Services (HHS) published a final rule implementing Section 1557 on June 19, 2020. 85 FR 37160 (codified at 45 C.F.R. § 92).

164. Section 1557 prohibits discrimination on the basis of disability in certain health programs and activities. 45 C.F.R. § 92.

165. Section 1557 states, in pertinent part, that “[t]he enforcement mechanisms provided for and available under...Section 504 [of the Rehabilitation Act of 1973] ...shall apply for purposes of violations of this subsection.” 42 U.S.C. § 18116 (a).

166. NY DOH was, at all times relevant to this action, and is currently a recipient of federal financial assistance within the meaning of Section 1557 of the ACA.

167. NY DOH provided and provides a “health program or activity” where “health program or activity” is defined as “encompass[ing] all of the operations of entities principally engaged in the business of providing healthcare that receive Federal financial assistance....For any entity not principally engaged in the business of providing healthcare, the requirements applicable to a “health program or activity” under this part shall apply to such entity’s operations only to the extent any such operation receives Federal financial assistance.” 45 C.F.R. § 92.3(b).

168. Section 1557 adopts the definition of disability from Section 504 of the Rehabilitation Act. 45 C.F.R. § 92.2(b)(4)

169. Chronic ventilator users who seek acute medical care in New York State are individuals with disabilities under Section 1557 of the ACA.

170. NY DOH's Guidelines violate Section 1557 of the ACA's prohibition on discrimination "under any health program or activity receiving Federal financial assistance...on the grounds of...disability." 45 C.F.R. § 92.1.

171. As a result of NY DOH's acts and omissions, chronic ventilator users seeking acute medical care in New York State have and will continue to be excluded from participation in, denied the benefits of, and subjected to discrimination from a healthcare system subject to the NY DOH Guidelines.

#### **PRAYER FOR RELIEF**

WHEREFORE, Plaintiffs request relief that the Court:

1. Assume jurisdiction and venue regarding this matter;
2. Certify this action as a class action pursuant to Fed. R. Civ. P. 23(a) and (b)(2) with respect to the proposed class identified herein;
3. Issue a declaratory judgment, in accordance with 28 U.S.C. § 2201 and Fed. R. Civ. P. 57, declaring that the Defendant's actions and failures or refusals to act violate federal law, as follows: that NY DOH's Ventilator Allocation Guidelines have subjected and continue to subject people with disabilities seeking acute healthcare in New York State to discrimination in violation of Title II of the ADA, Section 504, and Section 1557 of the ACA.
4. Enter temporary, preliminary, and permanent injunctive relief, pursuant to 28 U.S.C. § 2202 and Fed. R. Civ. P. 65, directing the NY DOH to issue new Ventilator Allocation

Guidelines that explicitly prohibit the reallocation of personal ventilators from chronic ventilator users to other individuals.

5. An award of reasonable attorneys' fees and costs; and
6. Such other further relief as deemed just and proper.

DATED: Brooklyn, NY  
October 7, 2020

Respectfully submitted,

/s/ Britney Wilson

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