

December 16, 2020

Dr. Scott Harris, State Health Officer
Alabama Department of Public Health
PO Box 303017
Montgomery, AL 36130-3017

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Harris,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Alabama Department of Public Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Alabama's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Alabama's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Alabama to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

¹ Cao, Michelle, et. Al, "Pulmonary Support for Neuromuscular Disease Patients During COVID19 Pandemic, Retrieved From https://www.mda.org/sites/default/files/2020/03/MDA-Guidelines-for-Healthcare-Pros_PulmonarySupport-Neuromuscular-Disease-Patients-COVID-19.pdf

² Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions, Retrieved from: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Alabama include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

Sincerely,

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Parent Project Muscular Dystrophy
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³ Jacob, Sujaih, et. Al. Guidance for the management of myasthenia gravis (MG) and Lambert-Eaton myasthenic syndrome (LEMS) during the COVID-19 pandemic: Journal of the Neurological Sciences: Volume 412, 116803, May 15, 2020 <https://doi.org/10.1016/j.jns.2020.116803>.

⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Mr. Adam Crum, Commissioner
Alaska Department of Health & Social Services
3601 C Street Suite 902
Anchorage, AK 99503-5923

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Mr. Crum,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Alaska Department of Health & Social Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Alaska's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Alaska's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Alaska to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Alaska include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Mr. Motusa Tuileama Nua, Director Department of Health
American Samoa Government
Executive Office Building
Pago Pago, AS 96799

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Mr. Nua,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the American Samoa Government for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of American Samoa's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of American Samoa's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request American Samoa to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that American Samoa include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Cara Christ, Director
Arizona Department of Health Services
Office of the Director 150 N 18th Avenue
Phoenix, AZ 85007

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Christ,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Arizona Department of Health Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Arizona's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Arizona's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Arizona to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Arizona include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Mr. Nathaniel Smith, Director and State Health Officer
Arkansas Department of Health
4815 W Markham Street
Little Rock, AK 72205-3867

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Mr. Smith,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Arkansas Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Arkansas's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Arkansas's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Arkansas to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Arkansas include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Ms. Sandra Shewry, Director
California Department of Public Health
PO Box 997377 MS 0500
Sacramento, CA 95899-7377

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Shewry,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the California Department of Public Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of California's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of California's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request California to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that California include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Allison Arwady, Commissioner
Chicago Department of Public Health
333 S State Street Room 200
Chicago, IL 60604

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Arwady,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Chicago Department of Public Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Chicago's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Chicago's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Chicago to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Chicago include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Ms. Dianne Herrero, Deputy Director
Colorado Department of Public Health
4300 Cherry Creek Drive
South Denver, CO 80246

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Herrero,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Colorado Department of Public Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Colorado’s vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

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We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Colorado’s vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Colorado to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as “might be at an increased risk” for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Colorado include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Ms. Molly Magarik, Secretary
Delaware Health and Social Services
1901 N Du Pont Highway
New Castle, DE 19720

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Magarik,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Delaware Health and Social Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Delaware's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Delaware's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Delaware to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Delaware include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Ms. Courtney Coppola, Chief of Staff
Florida Health Department
4052 Bald Cypress Way, Bin #C07
Tallahassee, FL 32311

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Coppola,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Florida Health Department for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Florida’s vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Florida’s vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Florida to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as “might be at an increased risk” for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Florida include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Kathleen Toomey, Commissioner
Georgia Department of Public Health
2 Peach Street NW, 15th Floor
Atlanta, GA 30303

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Toomey,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Georgia Department of Public Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Georgia's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Georgia's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Georgia to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Georgia include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Division of COVID-19
Guam Department of Public Health and Social Services
123 Chalan Kareta
Mangilao, Guam 96913-6304

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Division of COVID-19,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Guam Department of Public Health and Social Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Guam's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Guam's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Guam to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Guam include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Elizabeth Char, Director of Health
Hawaii State Department of Health
1250 Punchbowl Street
Honolulu, HI 96813

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Char,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Hawaii State Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Hawaii's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Hawaii's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Hawaii to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Hawaii include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Mr. Stephen Williams, Director
Houston Health Department
8000 N Stadium Drive
Houston, TX 77054

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Mr. Williams,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Houston Health Department for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Houston's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Houston's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Houston to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Houston include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Mr. Dave Jeppesen, Director
Idaho Department of Health and Welfare
PO Box 83720
Boise, ID 83720-0036

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Mr. Jeppesen,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Idaho Department of Health and Welfare for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Idaho's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Idaho's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Idaho to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Idaho include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Director's Office
Illinois Department of Public Health
Springfield Headquarters Office
525-535 West Jefferson Street
Springfield, IL 62761

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Director's Office of the Illinois Department of Public Health,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Illinois Department of Public Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Illinois's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Illinois's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Illinois to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Illinois include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Kristina Box, Health Commissioner
Indiana Department of Health
2 N Meridian Street
Indianapolis, IN 46204

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Box,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Indiana Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Indiana's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Indiana's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Indiana to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Indiana include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

COVID-19 Response Team
Iowa Department of Public Health
321 E 12th Street 6th Floor
Des Moines, IA 50319

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear COVID-19 Response Team,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Iowa Department of Public Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Iowa's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Iowa's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Iowa to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Iowa include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Lee Norman, Secretary
Kansas Department of Health and Environment
Curtis State Office Building
1000 SW Jackson Street
Topeka, KS 66612

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Norman,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Kansas Department of Health and Environment for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Kansas's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Kansas's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Kansas to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated

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weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Kansas include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

COVID-19 Response Team,
Kentucky Cabinet for Health and Family Services
275 E Main Street, HS1CB
Frankfort, KY 40601

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear COVID-19 Response Team,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Kentucky Cabinet for Health and Family Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Kentucky's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Kentucky's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Kentucky to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Kentucky include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Courtney Phillips, Secretary
Louisiana Department of Health
PO Box 629
Baton Rouge, LA 70821-0629

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Phillips,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Louisiana Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Louisiana's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Louisiana's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Louisiana to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Louisiana include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Nirav Shah, Director
Maine Department of Health and Human Services
109 Capitol Street
11 State House Station
Augusta, ME 4333

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Shah,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Maine Department of Health and Human Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Maine's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Maine's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Maine to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated

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weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Maine include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Mr. Philip Muller, Minister of Health
Ministry of Health
Republic of The Marshall Islands
PO Box 16
Majuro, MH 96960

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Mr. Muller,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Ministry of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Marshall Islands' vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Marshall Islands' vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Marshall Islands to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Marshall Islands include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Mr. Robert Neall, Secretary of Health
Maryland Department of Health
201 W Preston Street
Baltimore, MD 21201

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Mr. Neall,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Maryland Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Maryland's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Maryland's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Maryland to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Maryland include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Monica Bharel, Commissioner
Massachusetts Department of Public Health
250 Washington Street
Boston, MA 2108

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Bharel,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Massachusetts Department of Public Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Massachusetts's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Massachusetts's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Massachusetts to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Massachusetts include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Mr. Bob Swanson, Director
Michigan Department of Health & Human Services
333 S Grand Avenue
PO Box 30195
Lansing, MI 48909

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Mr. Swanson,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Michigan Department of Health & Human Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Michigan's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Michigan's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Michigan to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated

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weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Michigan include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

The Honorable Joses Gallen, Secretary
National Government of the Federated States of Micronesia
Department of Health and Social Affairs
PS70 Palikir
Pohnpei State, FM 96941

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Secretary Gallen,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Federated States of Micronesia for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Micronesia's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Micronesia's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Micronesia to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Micronesia include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Ms. Jan Malcolm, Commissioner
Minnesota Department of Health
PO Box 64975
St Paul, MN 55164-0975

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Malcolm,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Minnesota Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Minnesota's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Minnesota's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Minnesota to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Minnesota include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Mr. Jim Craig, Senior Deputy
Mississippi State Department of Health
PO Box 1700
Jackson, MS 39215-1700

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Mr. Craig,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Mississippi State Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Mississippi's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Mississippi's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Mississippi to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Mississippi include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Randall Williams, Director
Missouri Department of Health and Senior Services
912 Wildwood PO Box 570
Jefferson City, MO 65102

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Williams,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Missouri Department of Health and Senior Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Missouri's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

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We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Missouri's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Missouri to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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² Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions, Retrieved from: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Missouri include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Ms. Sheila Hogan, Director
Montana Department of Public Health and Human Services
111 North Sanders Street
Helena, MT 59601-4520

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Hogan,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Montana Department of Public Health and Human Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Montana’s vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Montana’s vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Montana to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as “might be at an increased risk” for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Montana include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Ms. Dannette Smith, Chief Executive Officer
Nebraska Department of Health & Human Services
301 Centennial Mall South
Lincoln, NE 68508

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Smith,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Nebraska Department of Health & Human Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Nebraska's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Nebraska's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Nebraska to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Nebraska include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Ihsan Azzam, Chief Medical Officer
Nevada Department of Health and Human Services
4126 Technology Way, Suite 100
Carson City, NV 89706-2009

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Azzam,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Nevada Department of Health and Human Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Nevada's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Nevada's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Nevada to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Nevada include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Ms. Kathleen Dunn, Associate Commissioner
New Hampshire Department of Health and Human Services
129 Pleasant Street
Concord, NH 3301

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Dunn,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the New Hampshire Department of Health and Human Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of New Hampshire's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of New Hampshire's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request New Hampshire to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that New Hampshire include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Ms. Judith Persichilli, Health Commissioner
New Jersey Department of Health
PO Box 360
Trenton, NJ 08625-0360

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Persichilli,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the New Jersey Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of New Jersey's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of New Jersey's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request New Jersey to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that New Jersey include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Ms. Susan Baum, Medical Director
New Mexico Department of Health
1190 S St Francis Drive
Santa Fe, NM 87505

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Baum,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the New Mexico Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of New Mexico's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of New Mexico's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request New Mexico to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that New Mexico include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Mr. Dave Chokshi, Health Commissioner
New York City Department of Health & Mental Hygiene
42-09 28th Street
Queens, NY 11101

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Mr. Chokshi,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the New York City Department of Health & Mental Hygiene for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of New York City’s vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of New York City’s vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request New York City to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as “might be at an increased risk” for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that New York City include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Mr. Howard Zucker, Health Commissioner
New York State Department of Health
Corning Tower Empire State Plaza
Albany, NY 12237

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Mr. Zucker,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the New York State Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of New York's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of New York's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request New York to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that New York include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Elizabeth Cuervo Tilson, Health Director and Chief Medical Officer
North Carolina Department of Health and Human Services
1050 Umstead Drive
Raleigh, NC 27603

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Cuervo Tilson,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the North Carolina Department of Health and Human Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of North Carolina's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of North Carolina's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request North Carolina to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that North Carolina include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Ms. Juli Sickler, Emergency Preparedness Division Director
North Dakota Department of Health
600 E Boulevard Avenue
Bismarck, ND 58505-0200

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Sickler,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the North Dakota Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of North Dakota's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of North Dakota's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request North Dakota to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that North Dakota include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Ms. Esther Muna, Chief Executive Officer
Commonwealth of the Northern Mariana Island
Commonwealth Healthcare Corporation
PO Box 500409 CK
Saipan, MP 96950

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Muna,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Commonwealth Healthcare Corporation for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of the Northern Mariana Islands' vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of the Northern Mariana Islands' vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request the Northern Mariana Islands to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated

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weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that the Northern Mariana Islands include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Ms. Stephanie McCloud, Director
Ohio Department of Health
Office of the Medical Director
246 N High Street
Columbus, OH 43215

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. McCloud,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Ohio Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Ohio's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Ohio's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Ohio to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Ohio include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Lance Frye, Interim Commissioner
Oklahoma State Department of Health
1000 NW 10th Street
Oklahoma City, OK 73104

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Frye,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Oklahoma State Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Oklahoma's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Oklahoma's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Oklahoma to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Oklahoma include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Ms. Rachael Banks, Director
Oregon Health Authority
Public Health Division
800 NE Oregon Street
Portland, OR 97232

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Banks,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Oregon Health Authority for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Oregon's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

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We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Oregon's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Oregon to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Oregon include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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³ Jacob, Sujaih, et. Al. Guidance for the management of myasthenia gravis (MG) and Lambert-Eaton myasthenic syndrome (LEMS) during the COVID-19 pandemic: Journal of the Neurological Sciences: Volume 412, 116803, May 15, 2020 <https://doi.org/10.1016/j.jns.2020.116803>.

⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Emais Roberts, Minister of Health
Palau Ministry of Health
One Hospital Road
PO Box 6027
Koror, Republic of Palau 96940

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Roberts,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Palau Ministry of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Palau's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Palau's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Palau to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Palau include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Rachel Levine, Secretary of Health
Pennsylvania Department of Health
30 Kline Village
Harrisburg, PA 17104

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Levine,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Pennsylvania Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Pennsylvania's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Pennsylvania's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Pennsylvania to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Pennsylvania include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Thomas Farley, Health Commissioner
Philadelphia Department of Public Health
1101 Market Street 13th Floor
Philadelphia, PA 19107

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Farley,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Philadelphia Department of Public Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Philadelphia’s vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Philadelphia’s vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Philadelphia to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as “might be at an increased risk” for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Philadelphia include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Lorenzo Gonzalez Feliciano, Secretary of Health
Puerto Rico Department of Health
1111 Calle Teniente César Luis González
San Juan, PR 00936-8184

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Gonzalez Feliciano,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Puerto Rico Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Puerto Rico's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Puerto Rico's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Puerto Rico to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Puerto Rico include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Nicole Alexander-Scott, Director
Rhode Island Department of Health
3 Capitol Hill
Providence, RI 2908

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Alexander-Scott,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Rhode Island Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Rhode Island's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Rhode Island's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Rhode Island to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Rhode Island include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Colleen Bridger, Interim Director and Assistant City Manager
San Antonio Metropolitan Health District
111 Soledad Suite 1000
San Antonio, TX 78205

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Bridger,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the San Antonio Metropolitan Health District for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of San Antonio's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of San Antonio's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request San Antonio to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that San Antonio include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Brannon Traxler, Interim Director of Public Health
South Carolina Department of Health and Environmental Control
2600 Bulls Street
Columbia, SC 29201

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Traxler,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the South Carolina Department of Health and Environmental Control for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of South Carolina's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of South Carolina's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request South Carolina to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that South Carolina include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Ms. Kim Malsam-Rysdon, Secretary
South Dakota Department of Health
600 E Capitol Avenue
Pierre, SD 57501-2536

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Malsam-Rysdon,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the South Dakota Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of South Dakota's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of South Dakota's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request South Dakota to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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² Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions, Retrieved from: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that South Dakota include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Lisa Piercey, Health Commissioner
Tennessee Department of Health
710 James Robertson Parkway
Nashville, TN 37243

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Piercey,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Tennessee Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Tennessee’s vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Tennessee’s vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Tennessee to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as “might be at an increased risk” for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Tennessee include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Nancy Ejuma, Deputy Associate Commissioner
Texas Department of State Health Services
PO Box 149347
Austin, TX 78714-9347

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Ejuma,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Texas Department of State Health Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Texas's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Texas's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Texas to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Texas include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Ms. Justa Encarnacion, Commissioner
United States Virgin Islands Department of Health
St Thomas / St John Office
1303 Hospital Ground Suite 10, Charlotte Amalie
St Thomas, VI 802

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Encarnacion,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the United States Virgin Islands Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of the United States Virgin Islands' vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of the United States Virgin Islands' vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request the United States Virgin Islands to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated

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weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that the United States Virgin Islands include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Joseph Miner, Executive Director
Utah Department of Health
Cannon Health Building 288 North 1260 West
Salt Lake City, UT 84116

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Miner,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Utah Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Utah’s vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Utah’s vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Utah to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as “might be at an increased risk” for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Utah include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Mark Levine, Health Commissioner
Vermont Department of Health
108 Cherry Street
Burlington, VT 5402

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Levine,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Vermont Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Vermont's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Vermont's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Vermont to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Vermont include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Parham Jaber, Chief Deputy Commissioner
Virginia Department of Health
109 Governor Street
Richmond, VA 23219

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Jaber,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Virginia Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Virginia's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Virginia's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Virginia to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Virginia include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Laquanda Nesbitt, Director
District of Columbia Department of Health
899 N Capitol Street
District of Columbia, Washington, DC 20002

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Nesbitt,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the District of Columbia Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Washington DC's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Washington DC's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Washington DC to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Washington DC include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Dr. Kathy Lofy, State Health Officer and the Chief Science Officer
Washington State Department of Health
111 Israel Road SE
Tumwater, WA 98501

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Lofy,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Washington State Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Washington's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Washington's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Washington to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Washington include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Dr. Ayne Amjad, Commissioner
West Virginia Bureau for Public Health
Office of Commissioner
350 Capitol Street, Room 702
Charleston, WV 25301

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Dr. Amjad,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the West Virginia Bureau for Public Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of West Virginia's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of West Virginia's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request West Virginia to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated

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weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that West Virginia include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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December 16, 2020

Ms. Susan Uttech, Public Health Standards Director
Wisconsin Department of Health Services
1 W Wilson Street
Madison, WI 53703

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Uttech,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Wisconsin Department of Health Services for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Wisconsin's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Wisconsin's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Wisconsin to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

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myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Wisconsin include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions

December 16, 2020

Ms. Stephanie Pyle, Senior Administrator
Wyoming Department of Health
401 Hathaway Building
Cheyenne, WY 82002

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Ms. Pyle,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank the Wyoming Department of Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Wyoming's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Wyoming's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Wyoming to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require

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immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Wyoming include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

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