February 13, 2025

The Honorable Matthew J. Memoli, M.D., M.S.
Acting Director
National Institutes of Health
9000 Rockville Pike,
Bethesda, Maryland 20892

Re: NOT-OD-25-068: Supplemental Guidance to the 2024 NIH Grants Policy Statement: Indirect Cost Rates

Dear Acting Director Memoli,

On behalf of the approximately 300,000 Americans living with a neuromuscular disease (NMD), the undersigned 40 patient advocacy organizations strongly urge the National Institutes of Health (NIH) to immediately reverse and retract "Supplemental Guidance to the 2024 NIH Grants Policy Statement: Indirect Cost Rates" that caps the coverage of indirect costs to 15 percent of

the grant. We believe this policy will catastrophically harm the neuromuscular disease research, drug development, and care ecosystem.

The NIH, and the hundreds-of-millions of dollars of neuromuscular disease basic and translational research that it funds each year, is at the very heart of the delicate research ecosystem that provides the neuromuscular disease community with the hope for better treatments and approaches to care. NIH-funded research has been instrumental in discovering the underpinnings of neuromuscular diseases, often identifying the genetic mutation or disease etiology responsible for our community's experiences. NIH-funded research has contributed to most, if not all, of the nearly thirty FDA-approved treatments available for our community. For those still awaiting their first approved treatment, NIH-funded research could prove critical in finding life-changing breakthroughs.

This cap on indirect costs within NIH grants could jeopardize the health and wellbeing of not only today's neuromuscular disease community, but generations to come. Coverage of indirect costs ensures labs are kept clean and compliant, support functions are completed, rent is paid, and many additional inherent costs to conducting research are covered. Without these funds, research may be stopped, labs may shut down, clinical trials may be halted, future doctors will not be trained, and progress may be stalled altogether.

On behalf of our community, we urge the NIH to immediately reverse this harmful cut to research. For questions regarding the above viewpoints, please contact Paul Melmeyer, EVP, Public Policy and Advocacy at the Muscular Dystrophy Association at pmelmeyer@mdausa.org.

Sincerely,

All Wheels Up
ALS Association
ALS Network
ALS United Greater Chicago
ALS United Greater New York
ALS United Mid-Atlantic
Answer ALS
Charcot-Marie-Tooth Association (CMTA)
Charlie's Cure
CMT Research Foundation
Coalition to Cure Calpain 3
Conquer MG
Cure CMD
CureLGMD2i Foundation
A Foundation Building Strength for Nemaline Myopathy
Friedreich's Ataxia Research Alliance (FARA)
FSHD Society
Genetic ALS & FTD: End the Legacy
Hereditary Neuropathy Foundation
Jain Foundation

Kennedys Disease Association
Les Turner ALS Foundation
LGMD Awareness Foundation
LGMD2D Foundation
LGMD2L Foundation
Little Hercules Foundation
MG Ohio
Muscular Dystrophy Association
Myasthenia Gravis Association
Myasthenia Gravis Foundation of America (MGFA)
Myasthenia Gravis Foundation of Michigan (MG-MI.org)
Myasthenia Gravis Holistic Society
The Myositis Association
Myositis Support and Understanding
Myotonic Dystrophy Foundation
National Ataxia Foundation
OPMD Association
Parent Project Muscular Dystrophy
The Speak Foundation
United Mitochondrial Disease Foundation

CC:

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Lindsey A. Criswell, M.D., M.P.H., D.Sc., Director, National Institute of Arthritis and Musculoskeletal and Skin Diseases
Diana W. Bianchi, M.D., Director, Eunice Kennedy Shriver National Institute of Child Health and Human Development
Joni L. Rutter, Ph.D., Director, National Center for Advancing Translational Sciences