July 13, 2026

Russell Vought, Director
Office of Management and Budget
Executive Office of the President
725 17th Street NW
Washington, DC 20503

Re: Neuromuscular Disease Patient Advocacy Organization Comments on the "Regulation for Federal Financial Assistance" Proposed Rule – Docket No. OMB-2026-0034-0001

Dear Director Vought;

The undersigned 35 patient advocacy organizations who collectively serve the neuromuscular disease (NMD) patient community are grateful for the opportunity to provide comments on the proposed rule entitled, "Regulation for Federal Financial Assistance" issued by the Office of Management and Budget (OMB) on May 29th, 2026. **Overall, the proposed rule may dramatically weaken the neuromuscular disease biomedical research infrastructure. We ask that you withdraw the rule.**

Neuromuscular diseases, all of which are rare diseases, feature progressive muscle weakening, many severe enough to lead to significant morbidities and shortened lifespans. Most neuromuscular diseases are genetic, and as decades of research investments have led to discoveries on disease underpinnings and etiology, we have learned more about the unique nature of each rare and ultra-rare neuromuscular diseases.

While we have made substantial progress in biopharmaceutical and clinical approaches to treating neuromuscular diseases, much work remains. Leading neuromuscular disease researchers agree that the proposed rule would weaken the scientific rigor, stability, and collaborative foundation of the biomedical research ecosystem that has been essential to advancing discoveries and therapies for people living with neuromuscular diseases.

The proposed rule diminishes the role of rigorous, science-based reviews of grants in favor of political considerations: We are greatly concerned with section "200.205 – Federal Agency Review of Merit of Proposals" and all potential subsequent Agency-specific sections that substantially reduces the role of science-based grant review processes in favor of political considerations focused on the current or future administration's priorities. Such a change risks undermining the scientific integrity and transparency of federally supported research. Neuromuscular diseases are individually rare and have long been underfunded by the Federal government, and progress has only been possible through sustained merit-based funding that supports scientifically rigorous research, regardless of political affiliation. Any proposal that could further de-emphasize research funding for neuromuscular diseases if not deemed an administration's priority is unacceptable and threatens decades of progress for patients with rare neuromuscular diseases.

Our community needs the assurance that the research funded by the National Institutes of Health (NIH), the Food and Drug Administration (FDA), the Centers for Disease Control and Prevention (CDC) and the Department of Defense's Congressionally-Directed Medical Research Program (CDMRP) is rigorously evaluated and is the best possible option for community support and participation. The proposed rule states that "gold-standard science" will be funded, but does not define the term, nor explain why our current system of rigorous peer-review and multiple stages of scientific evaluation is inadequate.

The proposed rule allows for grants to be terminated at any time for any reason: Several sections within the rule (namely sections 200.230, 200.231, and 200.232) allow Federal institutions to pause, suspend, or even terminate grants at any time for any reason. This is simply unacceptable to our community.

The neuromuscular disease community frequently makes difficult and complex decisions on participating in clinical research, weighing the benefits and risks and deciding whether the opportunity is right for them or their child. The prospect of a research study being abruptly terminated in the middle of participation because it no longer aligns with opaque political priorities is unconscionable to those donating their time, energy, and health to advance scientific understanding.

Furthermore, neuromuscular disease research often takes several years to reach a conclusion. If this research spans multiple administrations, it is of great risk of being terminated in the midst of the study, thus potentially risking any multi-year effort oftentimes necessary in progressive neuromuscular diseases.

The proposed rule disallows Federal grants to fund research that intersect with diversity, equity, and inclusion: The proposed disallowance of Federal research grants from funding research intersecting diversity, equity, and inclusion could have various consequences on our communities. Our communities often face difficulties in obtaining a diagnosis, accessing care, qualifying for clinical trials, and more. Research into these challenges is needed to understand how we as a community and policymakers can craft solutions to ensure everyone in our communities receive timely access to diagnoses, treatments, care, and services. Furthermore, we are concerned that this proposed prohibition could impede research into the etiology and treatment of neuromuscular diseases and how they may differ across sexes.

The proposed rule greatly limits grant funding from being used to attend scientific conferences and publish findings in journals: Collaboration and the dissemination of research findings is critical in rare and ultra-rare communities, and the provision that limits the ability to use grant funds to attend conferences and publish in journals will only serve to stifle collaboration.

Often our organizations are the leading, perhaps only, organizations convening the research community to discuss research findings and discoveries at our conferences. We routinely see the research community learning from each other and crafting collaborations when gathered at our conferences. If they are prohibited from using grant funding to attend, such collaborations may never occur.

Researchers also publish in scientific journals to disseminate the findings of the research for the entire community to digest. The limitations in this provision for using grant funds to publish research may also severely impede our disease areas from being better understood.

The proposed rule greatly limits foreign collaborations on Federally-funded grants: Given the rarity of neuromuscular diseases, global collaborations are often needed to not only include the needed number of patients in clinical or biomedical research studies, but also the needed number of scientific collaborators as there only may be a small handful of U.S.-based researchers working on an ultra-rare neuromuscular condition. This proposal could greatly impede the neuromuscular research community from collaborating with colleagues in other countries who are researching neuromuscular conditions, thus once again placing barriers in front of scientific discovery as well as biopharmaceutical and clinical advancements.

In totality, this proposed rule creates numerous barriers, impediments, and substantial instabilities to the neuromuscular disease research ecosystem. We ask that you withdraw the rule. For questions on our viewpoints and experiences, please contact Paul Melmeyer, Executive Vice President, Public Policy and Advocacy, Muscular Dystrophy Association, at pmelmeyer@mdausa.org

Sincerely,

All Wheels Up
ALS Association
ALS Network
ALS United
Answer ALS Foundation
CMT Research Foundation
CMTA (Charcot-Marie-Tooth Association)
Coalition to Cure Calpain 3
Cure CMD
Cure LGMD2i Foundation
Cure VCP Disease
A Foundation Building Strength
FSHD Society
Hereditary Neuropathy Foundation
I AM ALS
Jain Foundation
Kennedy's Disease Association
Kindness Over Muscular Dystrophy
Les Turner ALS Foundation
LGMD Awareness Foundation
LGMD2D Foundation
MitoAction
Muscular Dystrophy Association
Myasthenia Gravis Association
Myasthenia Gravis Foundation of America
The Myositis Association
Myositis Support and Understanding
Myotonic Dystrophy Foundation (MDF)
National Ataxia Foundation
OPMD Association
Parent Project Muscular Dystrophy
The Speak Foundation
Team Joseph
Team Titin, Inc.
United Mitochondrial Disease Foundation