Huntington's Disease Society of America

July 6, 2026

Office of Management and Budget

To Whom It May Concern:

On behalf of the Huntington's Disease Society of America (HDSA), I am writing to express strong opposition to several provisions included in the proposed revisions to the Uniform Guidance.

These changes would have significant negative consequences for biomedical research, particularly for the Huntington's disease community and the broader rare disease communities that depend on sustained federal investment and scientific independence to advance treatment development.

HDSA is a leading national organization dedicated to the care and cure of Huntington's disease (HD), a rare and fatal hereditary disorder that manifests as a neurological disease with both physical and psychiatric components. If one parent has HD, their children have a 50 percent chance of inheriting HD. Our focus is to promote and support research to find a cure for HD; help people and families affected by the disease; and educate the public and healthcare professionals about HD.

Currently, there is no clinically available pharmacological, biological, or surgical agent or method which slows or stops the progression of HD. HDSA supports continued research to better understand HD, as well as improve access to quality treatment by financially supporting 60 HDSA Centers of Excellence and 9 Clinical Partner Sites covering 37 states plus the District of Columbia. HDSA has a long history of supporting people living with HD and family members through a network of 47 Chapters and Affiliates that provide access to more than 120 locally-based social workers and 100 support groups around the country.

Section §200.205 – Political Review of Discretionary Grant Awards
I am concerned by the proposal to require senior political appointees to review discretionary grant awards to determine alignment with Administration priorities and executive orders. Federal research funding decisions should be guided by scientific merit, patient need, and rigorous peer review. Allowing political considerations to override expert scientific evaluation risks undermining public confidence in the research enterprise and could discourage innovative or high-risk research that may not align with shifting political priorities.

For Huntington's disease and other rare diseases, additional political review may further disadvantage smaller patient populations whose scientific needs may not be viewed as

immediate national priorities despite the profound impact these diseases have on affected patients and families.

Section §200.340 – Expanded Grant Termination Authority
I strongly oppose the proposed expansion of agency authority to terminate active awards when a project is deemed inconsistent with agency priorities, program goals, or national interest.

Biomedical research often spans many years and requires substantial investments of time, personnel, infrastructure, and participant engagement. The possibility that grants could be terminated mid-project based on changing priorities creates significant uncertainty for researchers and institutions. It may also discourage patient participation in research studies if participants cannot be confident that studies will be completed as promised.

Huntington's disease research is especially vulnerable because progress frequently depends on long-term natural history studies, multi-year clinical trials, and collaborative data collection efforts. This policy also poses the risk of patients not wanting to participate in studies if projects are terminated leading to less patient participation in research studies. Terminating grants after substantial investments have been made could delay scientific advances and waste taxpayer resources already committed to these projects.

Sections §200.432 and §200.461 – Conference Attendance and Publication Restrictions
I am concerned about the proposed restrictions on conference attendance and publication costs. Scientific conferences provide critical opportunities for researchers, clinicians, patient organizations, and federal partners to share findings, develop collaborations, and accelerate innovation. For rare diseases, conferences often represent one of the few opportunities for geographically dispersed experts to meet and coordinate research efforts.

Similarly, publication costs and open-access fees are essential components of modern scientific communication. Restricting reimbursement for publication expenses unless specifically approved could slow dissemination of research findings and limit access to federally funded discoveries. Patients, caregivers, clinicians, and researchers all benefit when scientific information is shared broadly and efficiently.

Section §200.202 – Program Alignment with Administration Priorities
While federal agencies should have flexibility to establish strategic priorities, the proposed emphasis on alignment with Administration priorities raises concerns that funding decisions could become overly influenced by short-term political objectives rather than long-term scientific opportunities and public health needs.

Huntington's Disease Society of America

Research priorities should be informed by scientific evidence, disease burden, patient needs, and expert review. Stable and predictable funding policies are particularly important for the Huntington's disease community where scientific progress often requires decades of sustained investment.

Anticipated Impact

If implemented, these provisions could weaken the nation's biomedical research enterprise by creating uncertainty around funding decisions, discouraging innovative research, reducing collaboration, and limiting dissemination of scientific findings. For Huntington's disease and the broader rare disease communities, these changes could delay the development of desperately needed treatments and reduce opportunities for patients to participate in meaningful research.

The proposed rule may also make it more difficult for patient advocacy organizations, academic institutions, and research partners to plan long-term initiatives, recruit talented investigators, and maintain public trust in federally funded science.

Recommendation

I respectfully urge the Office of Management and Budget to withdraw or substantially revise the provisions contained in §§200.202, 200.205, 200.340, 200.432, and 200.461.

Federal grant-making should continue to be guided by scientific merit, expert peer review, transparency, and long-term public benefit. Any changes to the Uniform Guidance should strengthen—not weaken—the stability, independence, and effectiveness of the nation's research infrastructure.

Thank you for the opportunity to comment on this proposed rule.

Respectfully,

Amy Gray
President and Chief Executive Officer
Huntington's Disease Society of America