The Honorable Bill Cassidy, M.D.
Chairman, Senate Committee on Health, Education, Labor, and Pensions
United States Senate
Washington, D.C. 20510

The Honorable Bernie Sanders
Ranking Member, Senate Committee on Health, Education, Labor, and Pensions
United States Senate
Washington, D.C. 20510

Dear Chairman Cassidy and Ranking Member Sanders:

We, the undersigned organizations representing children with cancer, their families, and the researchers and clinicians who dedicate their careers to defeating childhood cancer, write to you with serious concern regarding the Office of Management and Budget's proposed Regulation for Federal Financial Assistance (Docket OMB-2026-0034, published May 29, 2026). If finalized, this rule would significantly impact the science that gives children with cancer their best chance at survival. We urge the Committee to carefully review and consider revisions to this proposed rulemaking before the July 13, 2026 comment deadline.

Background: What Is at Stake for Children with Cancer

Childhood cancer remains the leading cause of disease-related death among children in the United States. Progress against the most devastating pediatric malignancies depends entirely on a robust federal research enterprise. The National Cancer Institute, the National Institutes of Health, and the National Science Foundation collectively fund the foundational science, clinical trials, and translational research that underpin every advance in treatment. The children enrolled in those trials today are alive because of grants awarded years ago on the basis of scientific merit.

That merit-based system is now directly threatened.

Our Concerns

1. Senior Agency Officials Would Conduct Pre-Award Review Alongside Scientific Peer Review

The proposed rule (§200.205) would require senior agency appointees to conduct a mandatory pre-issuance review of every discretionary grant before it is awarded. These officials would be explicitly prohibited from deferring to peer reviewers or treating expert recommendations as

binding. Grants must, under the proposed text, "demonstrably advance the President's policy priorities."

Childhood cancer research has no partisan dimension. A grant to study the genomics of medulloblastoma or the long-term cardiac effects of doxorubicin in pediatric patients should be evaluated solely on scientific merit by experts who can assess its quality and potential. Subjecting such grants to non-scientific review criteria will result in meritorious projects being denied funding, not because they lack scientific rigor, but because a reviewing official determines they do not align with agency priorities.

2. Active Grants Can Be Terminated Mid-Award Without Cause

Section 200.340 codifies and expands the authority to terminate active grants simply because they are deemed "inconsistent with program goals or agency priorities." No finding of noncompliance, fraud, or scientific failure is required.

For childhood cancer research, this could lead to serious disruptions in treatment development. Multi-year clinical trials enroll vulnerable patients, hire specialized research staff, and build patient registries over many years. Abrupt mid-award termination not only wastes taxpayer money, but it abandons children who are mid-trial, erases years of data collection, and may expose enrolled patients to harm when continuity of care is disrupted. This rule would make the authority to cancel federal grants permanent, government-wide, and immune to challenge.

3. An Undefined "Gold Standard Science" Standard Invites Arbitrary Exclusion

The proposed rule repeatedly conditions grant awards on compliance with "Gold Standard Science" (§200.205), a term tied to Executive Order 14303 but never defined in concrete or measurable terms. Institutions must demonstrate success in implementing this undefined standard, yet no institution can reliably demonstrate compliance with a standard that lacks an objective definition.

Children's hospitals, academic medical centers, and research universities that conduct pediatric oncology research could find themselves disqualified not for scientific or fiduciary failures, but because a reviewing official determines, without defined criteria, that they have not sufficiently demonstrated compliance with the undefined "Gold Standard Science" requirement.

4. International Scientific Collaboration Would Be Severely Restricted

Childhood cancers are rare. No single country has sufficient patient populations to power the clinical trials needed to validate new therapies. International consortia have been indispensable to nearly every major advance in pediatric oncology over the past three decades.

The proposed rule (§200.220) would prohibit the use of any federal funds, including indirect costs, for collaboration with "covered foreign countries" and their affiliates. The “domestic-first” framework (§200.202(e)) further presumes that international elements in federally funded research are disfavored absent affirmative case-by-case approval from a designated agency official. These provisions would effectively end the international research partnerships that are not optional enhancements but structural necessities for rare pediatric diseases.

Our Requests

We respectfully urge the Committee to take the following actions:

- Hold oversight hearings on the OMB proposed rule and its specific impacts on federally funded health and biomedical research, with particular attention to pediatric disease research.
- Request that OMB withdraw or carefully revise the proposed rule to preserve merit-based, expert-driven peer review as the primary determinant of federal research grant awards.
- Enact protective legislation, if necessary, to codify the independence of the peer-review process for scientific grant awards and to prohibit mid-award termination of clinical trials absent a finding of misconduct or material noncompliance.
- Issue a formal Committee letter to OMB Director Russell Vought, transmitting the Committee's concerns and requesting detailed justification for each provision's application to NIH and NCI grant programs.
- Meet with our member organizations, pediatric cancer researchers, and the families of children currently enrolled in federally funded clinical trials who will be directly harmed if this rule is finalized.

The children we represent cannot wait. They are in treatment today, enrolled in trials today, and depending on the scientific enterprise that this rule would fundamentally restructure. We ask that you use every tool available to this Committee to protect the merit-based research system that gives them a fighting chance.

We welcome the opportunity to brief your staff, provide additional documentation, or facilitate meetings with affected families and researchers at your convenience. Please contact Michael Henry at mhenry@curethekids.org or (484) 326-8287 to arrange a meeting.

Respectfully submitted,

The Coalition Against Childhood Cancer
The Pediatric Brain Tumor Foundation
1Voice Foundation
Arms Wide Open Childhood Cancer Foundation
Association of Pediatric Hematology Oncology Nurses
Beat Childhood Cancer Foundation
Book for Hope, Inc.
Brave Like Mckenna
CancerFree KIDS
Cannonballs for Kayne Foundation
Carson Leslie Foundation
ChadTough Defeat DIPG Foundation
Cure 4 The Kids Foundation
CURE Childhood Cancer
CureSearch for Children's Cancer
Elevate Childhood Cancer Research and Advocacy, Inc.
Emily Whitehead Foundation
Grandparents In Action
Hope4ATRT
Kyra's Hope Foundation
LIVs Creative Legacy
Love Bus
MACC Fund
Magic for Maddie, Inc.
MIB Agents Osteosarcoma
Mithil Prasad Foundation
Mystic Force Foundation
Neev Kolte Foundation
Neuroblastoma Children's Cancer Society

Rett’s Roost
Ryan Mayer Coaching
Ryan's Case for Smiles
Solving Kids' Cancer
Swifty Foundation
Tatertough Foundation
The Andrew McDonough B+ Foundation
The Maddox Potter Foundation
This Star Won't Go Out
Ty Louis Campbell Foundation
Vivienne C. Finn Foundation
WITH Grace Initiative
Zach's Bridge
Zoefia Alexandria Foundation

cc: Members of the Senate HELP Committee; Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education; Office of Management and Budget, Docket OMB-2026-0034