Pediatric Brain Tumor FOUNDATION

Talking Points for Conversations with your Member of Congress

Use this guide to prepare for meetings with your Member of Congress or their staff. You do not need to cover every point — lead with your personal story, then use the talking points below to reinforce it. Aim for a 15–20 minute meeting.

1. Open the Meeting

- Thank the Member or staffer for their time and for any past support of pediatric brain tumor research or childhood cancer legislation (e.g., the STAR Act, RACE Act, Gabriella Miller Kids First Act).
- Introduce yourself and your connection to pediatric brain tumors — as a family member, survivor, clinician, researcher, or advocate. Personal stories are the most persuasive part of any meeting.
- State up front why you're there: "I'm here today because a proposed OMB rule threatens the federal research system that gives kids with brain tumors a fighting chance."

2. Make the Ask

Ask your Member of Congress to:

- Support congressional oversight of OMB's proposed rule (Docket OMB-2026-0034) and its impact on federally funded pediatric research.
- Request that OMB withdraw or substantially revise the rule to preserve merit-based, expert-driven peer review.
- Cosponsor or support legislation to codify peer-review independence and bar mid-award termination of research grants absent misconduct or noncompliance.
- Sign onto or send a letter to OMB Director Russell Vought requesting justification for how each provision applies to NIH and NCI grant programs.

3. Why This Matters — The Big Picture

- Childhood cancer is the leading cause of disease-related death among children in the United States.
- Progress against pediatric brain tumors, relapsed leukemias, and rare sarcomas depends on federal research funding from NIH, NCI, and NSF — funding that has always been awarded on scientific merit.
- Kids enrolled in clinical trials today are alive because of grants awarded years ago based on peer-reviewed science, not political considerations. This rule would put that system at risk.

4. Key Talking Points

Peer review could be overridden

- The rule would let senior agency officials block or delay any discretionary grant that doesn't "demonstrably advance" administration policy priorities, even when scientific reviewers recommend funding it.
- Say: "A grant to study medulloblastoma genomics or the heart effects of chemotherapy in kids shouldn't be evaluated on anything other than the science."

Active grants could be cancelled mid-award

- Grants could be terminated with no finding of fraud or noncompliance — just because an agency decides they're no longer a "priority."
- Say: "Multi-year clinical trials enroll real kids. Cutting off a trial mid-way doesn't just waste money — it can put patients who are already enrolled at risk and erase years of data."

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"Gold Standard Science" is undefined

- The rule conditions funding on compliance with a term that is never clearly defined, which opens the door to arbitrary decisions about who gets funded.
- Say: "Children's hospitals and universities could lose funding not because of bad science, but because no one can say what the standard actually requires."

International research collaboration would be restricted

- Because childhood cancers are rare, researchers depend on international partnerships to enroll enough patients for meaningful clinical trials. This rule would block federal funds from supporting that collaboration.
- Say: "No single country has enough pediatric cancer patients to run these trials alone. Cutting off international collaboration slows down cures for kids."

5. Anticipated Questions

Q: Doesn't the government need more accountability over how grant money is spent?

A: Accountability already exists. Grants go through rigorous scientific peer review, and agencies can act on real findings of fraud or noncompliance. This rule adds a layer of political review on top of that system and allows termination without any finding of wrongdoing.

Q: Isn't this just about NIH? Why should our office care about OMB rules generally?

A: The rule applies government-wide, but its impact would be felt directly through HHS (including NIH and FDA), the National Science Foundation, and the Department of Defense, all of which fund pediatric cancer-related research.

Q: What specifically do you want us to do right now?

A: Point back to the ask on page one: support oversight, ask OMB to revise or withdraw the rule, and support legislation protecting peer review and existing grants.

Q: Has the comment period closed?

A: Yes, the public comment period closed July 13, 2026. That's exactly why congressional oversight and legislative action are the next avenue. The rule can still be revised or blocked before it is finalized and implemented.

6. Close the Meeting

- Leave behind the one-page briefing document with the four key concerns and the ask.
- Ask for a follow-up commitment: "Can we count on your support for oversight of this rule?" or "Could your office follow up with OMB on our behalf?"
- Offer to be a resource: share your contact information and offer to connect their office with researchers, clinicians, or families for further information.
- Thank them again for their time.

Questions before your meeting? Contact: Michael Henry — mhenry@curethekids.org — (484) 326-8287