

Dr. Douglas Lowy, Principal Deputy Director, National Cancer Institute

cc: Dr. Malcolm Smith, Associate Branch Chief for Pediatric Oncology

Office of the Director

31 Center Drive, Building 31

Bethesda, Maryland, 20814

Dear Interim Director Lowy.

We are writing to you on behalf of our coalition dedicated to advocating for children and families affected by pediatric brain cancers. It is with deep concern and considerable disappointment that we learned of the National Cancer Institute's decision to end funding for the Pediatric Brain Tumor Consortium (PBTC).

Over the past 26 years, the PBTC has been instrumental in advancing research, fostering innovation, and providing hope for families battling this devastating disease. The consortium's collaborative efforts have been essential in addressing the unique challenges of pediatric brain tumors and have contributed significantly to our understanding and treatment of these complex conditions. The consortium's work has catalyzed numerous clinical trials and nurtured groundbreaking therapies that offer a lifeline to countless children and their families.

The decision to defund the PBTC threatens to stall critical research efforts and disrupt the momentum built over years of dedicated work. We recognize that this decision was not made lightly and appreciate NCI leadership's willingness to engage with advocates and answer questions from our community. However, we remain deeply concerned about the transition of active PBTC clinical trials and the stewardship of the consortium's invaluable data, particularly as it relates to the Pediatric Early Phase Clinical Trial Network (PEP-CTN).

Pediatric brain cancers remain the leading cause of cancer-related death among children. The stakes are too high for progress to be derailed. A clear, strategic, and immediate plan of action is not just necessary—it is critical to ensure that children retain access to the most promising treatments available.

We strongly urge the NCI take the following immediate actions:

- **Continued community engagement** – Work with advocates, clinicians, and researchers from the pediatric brain tumor field to help shape the transition plan and protect access to current patient treatments.

- **Safeguard ongoing trials** – Ensure that all PBTC trials currently underway are either completed or transitioned with full transparency into PEP-CTN or the COG-CNS working group, with active involvement of patient advocates to help guide decisions and ensure transitions occur without disruption to patient care or trial integrity.
- **Preserve critical data** – Develop and report a clear and transparent plan for the stewardship and accessibility of the decades of data, protocols, infrastructure and especially the biorepository, that PBTC has built over the past 26 years.
- **Dedicate resources for brain tumors** – Dedicate sufficient funding and expertise within PEP-CTN/COG-CNS to support pediatric brain tumor trial development, ensuring that this disease area remains a top priority at the federal level.

Our coalition, alongside countless families, medical professionals, and researchers, stands ready to support and engage in the necessary dialogue to secure a resolution. We believe that by working together, prioritizing innovation, and investing in research collaborations, we can change the landscape of pediatric brain cancer treatment for the better, offering hope and new possibilities for all affected.

Thank you for considering this request with the seriousness it deserves. We look forward to your response and to working in partnership to protect and strengthen pediatric brain tumor clinical research. If you have additional questions or need more information, please contact Michael Henry, Director of Advocacy for the Pediatric Brain Tumor Foundation at mhenry@curethekids.org

With urgency and respect,

The Pediatric Brain Tumor Foundation

American Society of Pediatric Hematology/Oncology

The Andrew McDonough B+ Foundation

Arms Wide Open Childhood Cancer Foundation

AYJ Fund

Book for Hope, Inc.

The Braden James Fund

Brain Tumor Network

Brave like McKenna Foundation

Carson Leslie Foundation

ChadTough Defeat DIPG Foundation

Children's Brain Tumor Network

Children's Cancer Cause

CURE Childhood Cancer

The Cure Starts Now Foundation

Dana-Farber Cancer Institute

Dragon Master Initiative

Elora J. Khan Foundation

Gift from a Child

Gilda's Club Kentuckiana

Hope4ATRT Foundation

Hope Through Hollis Foundation

Kentucky Pediatric Cancer Research Trust Fund

Kids Cancer Alliance, Inc.

Lilabeau Foundation for Pediatric Brain Cancer Research

Love for Linley Foundation, Inc.

Magic for Maddie, Inc.

McKenna Claire Foundation

The Medulloblastoma Initiative

The Morgan Adams Foundation

Mithil Prasad Foundation

Musella Foundation for Brain Tumor Research & Information, Inc.

The National Brain Tumor Society

Neev Kolte & Brave Ronil Foundation

Ollie's Orchestra

Princess Hailey's Hope Foundation

Rally Foundation for Childhood Cancer Research

Seth's Squad

The Society for Neuro-Oncology

Storm the Heavens Fund

Super Drew's Crew

Swiftly Foundation

TaterTough Foundation

Tough2Gether Foundation

Ty Louis Campbell Foundation

Unravel Pediatric Cancer

1Voice Foundation