



August 23, 2021

The Honorable Marco Rubio
United States Senate
284 Russell Senate Office Building
Washington, DC 20510

The Honorable Jack Reed
United States Senate
729 Hart Senate Office Building
Washington, DC 20515

Dear Senators Rubio and Reed,

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, healthcare professionals and scientific organizations, representing millions of Americans who care deeply about childhood cancer. We write to thank you for introducing and working to pass the Senate resolution to designate May 17th as “DIPG Awareness Day”. With the passage of this resolution, you and your colleagues are raising awareness and encouraging research into cures for diffuse intrinsic pontine glioma (DIPG) and pediatric cancers in general.

Diffuse Intrinsic Pontine Glioma is the leading cause of childhood brain tumor deaths. Every year, 130-300 children in the U.S. will be diagnosed with DIPG, and most of them will only survive nine months, or about as long as the typical school year. There is currently no consistent standard of care for these kids, and few treatments.

The Senate resolution designating a DIPG Awareness Day will help spread awareness about this deadly disease, and support researchers in their efforts to find new therapies to treat DIPG. In addition, the resolution proposes that private and public research funding “elevate the consideration of the mortality rate of a type of cancer” to ensure that research is funded to find treatments for those with the most challenging diseases.

While all childhood cancer is devastating, DIPG is a particularly terrible disease that leaves children and their families with limited options and limited time. Thank you for your dedication in passing this resolution to honor those children whose lives have been lost, and to encourage additional research to give hope for children diagnosed in the future.

Sincerely,

The Alliance for Childhood Cancer

American Cancer Society Cancer Action Network

American Childhood Cancer Organization



American Society of Pediatric Hematology/Oncology

The Andrew McDonough B+ Foundation

Association of Pediatric Hematology/Oncology Nurses

Association of Pediatric Oncology Social Workers

Children's Brain Tumor Foundation

Children's Cancer Cause

Children's Oncology Group

National Brain Tumor Society

Pediatric Brain Tumor Foundation

Rally Foundation for Childhood Cancer Research

St. Baldrick's Foundation