

PO Box 41913 Philadelphia, PA 19101

cac2.org

Board of Directors 2024-2025

EXECUTIVE COMMITTEE

Ginny McLean Board Chair Gift from a Child/Swifty Foundation

> Caitlyn Barrett Vice Chair Individual Member

Robin French Past Board Chair The Morgan Adams Foundation

Mariah Forster Olson Secretary – Survivorship Liaison Neuroblastoma Children's Cancer Society

BOARD MEMBERS

Lori Earl Family Support This Star Won't Go Out

Amy Godkin ASK Childhood Cancer Foundation

> Ashley Guthrie Austin Hatcher Foundation for Pediatric Cancer

> > **TJ Koerner** Individual Member

Susannah Koontz Speaker Coordinator Individual Member

Angela Lee National Advocacy Liaison Individual Member

Misha Mehta Neev Kolte & Brave Ronil Foundation

> Ann Ramer State Advocacy Liaison Individual Member

Aubrey Reichard-Eline With Grace Initiative

> Nicole Scobie Zoe4Life

EX OFFICIO MEMBERS OF THE BOARD

Vickie Buenger President Emeritus Individual Member

Steven L. Pessagno Treasurer/Development Lead Individual Member FOR IMMEDIATE RELEASE January 3, 2025

CONTACT:

Vickie Buenger 979-820-1755 presidentemeritus@cac2.org Angela Lee 210-383-6873 advocacy@cac2.org

The undersigned childhood cancer organizations are members of the Coalition Against Childhood Cancer (CAC2), whose members care deeply about all aspects of childhood cancer. Like our colleagues in many other organizations that support children and teens with cancer, we are deeply disappointed that Congress left kids with cancer behind in its end-of-year package. Congress had the opportunity to pass the most influential childhood cancer legislation in a decade – but instead, it cut out five critical bipartisan policies that would have benefited childhood cancer patients and their families.

Childhood Cancer is the #1 disease related killer of kids and teenagers in the U.S. One in five children diagnosed with cancer will die within five years of diagnosis. Since, on average, Americans live into their 70s, when children die of cancer, their families experience a full 70 years of expected life lost. Furthermore, one in 285 American children will be diagnosed with cancer before the age of 20, representing over 17,000 children. More than 95% of childhood cancer survivors will have significant health-related issues by the time they are 45 years of age. These health-related issues are side-effects of their cancer or, more commonly, the result of their treatment regimen.

The cuts made near the end of the legislative session include:

- The Accelerating Kids' Access to Care Act, which cuts bureaucratic red tape that keeps kids from accessing time-sensitive care across state lines;
- The Creating Hope Reauthorization Act, which incentivizes critical pediatric research, but whose funding has expired due to congressional inaction;
- The Innovation in Pediatric Drugs Act, to ensure pediatric studies for possible new treatments are completed on time—and brings us closer to cures;
- Give Kids A Chance Act, which allows researchers to study combinations of new cancer drugs, potentially unlocking new cures for kids; and
- The RARE Act, which clarifies Congress' interpretation of the Orphan Drug Act to ensure pediatric drug research and development isn't locked out from newly approved drugs that don't impact pediatric populations.

Together, these policies would have addressed some of the most pressing needs for children with cancer and their families: funding vital research programs, reducing



PO Box 41913 Philadelphia, PA 19101

cac2.org

Board of Directors 2024-2025

EXECUTIVE COMMITTEE

Ginny McLean Board Chair Gift from a Child/Swifty Foundation

> Caitlyn Barrett Vice Chair Individual Member

Robin French Past Board Chair The Morgan Adams Foundation

Mariah Forster Olson Secretary – Survivorship Liaison Neuroblastoma Children's Cancer Society

BOARD MEMBERS

Lori Earl Family Support This Star Won't Go Out

Amy Godkin ASK Childhood Cancer Foundation

> Ashley Guthrie Austin Hatcher Foundation for Pediatric Cancer

> > **TJ Koerner** Individual Member

Susannah Koontz Speaker Coordinator Individual Member

Angela Lee National Advocacy Liaison Individual Member

Misha Mehta Neev Kolte & Brave Ronil Foundation

> Ann Ramer State Advocacy Liaison Individual Member

Aubrey Reichard-Eline With Grace Initiative

> Nicole Scobie Zoe4Life

EX OFFICIO MEMBERS OF THE BOARD

Vickie Buenger President Emeritus Individual Member

Steven L. Pessagno Treasurer/Development Lead Individual Member bureaucratic delays to improve access to specialty care and clinical trials, and ensuring children with untreatable cancer have access to new life-saving cures.

We are disheartened that Congress eliminated this potential progress from their package – and with it, the hope that it represented for children with cancer. We request that when the 119th Congress is seated and the new session convenes on Jan. 3, 2025, children with cancer must be the first order of business. Children with cancer have waited long enough–it's time to finish the job.

The Coalition Against Childhood Cancer welcomes the opportunity to discuss the unique challenges of childhood cancer and legislation to help mitigate those challenges. We look forward to working with our Members of Congress to ensure our priorities are addressed as early in the new Session as possible. Should questions or requests for additional information arise, please contact Angela Lee, National Advocacy Lead at CAC2 (advocacy@cac2.org) or Vickie Buenger, President Emeritus at CAC2 (presidentemeritus@cac2.org).

The following organizations endorse this statement: Coalition Against Childhood Cancer A Moment of Magic Andrew McDonough B+ Foundation Association of Pediatric/Hematology Oncology Nurses Arms Wide Open Childhood Cancer Foundation Battlecorn Care Packages **Bear Necessities** Books for Hope Braden's Hope for Childhood Cancer Cancer Free Kids Carson Leslie Foundation Children's Cancer Cause Christing Renng Foundation CureSearch for Children's Cancer Dana Farber Cancer Institute Daniela Conte Foundation **Elaine Roberts Foundation** Elevate Childhood Cancer Research and Advocacy, Inc End Kids Cancer Evan's Victory Against Neuroblastoma Foundation Friends of Cathvrn Gabriella's Smile Foundation Hope4ATRT





PO Box 41913 Philadelphia, PA 19101

cac2.org

Board of Directors 2024-2025

EXECUTIVE COMMITTEE

Ginny McLean Board Chair Gift from a Child/Swifty Foundation

> Caitlyn Barrett Vice Chair Individual Member

Robin French Past Board Chair The Morgan Adams Foundation

Mariah Forster Olson Secretary – Survivorship Liaison Neuroblastoma Children's Cancer Society

BOARD MEMBERS

Lori Earl Family Support This Star Won't Go Out

Amy Godkin ASK Childhood Cancer Foundation

> Ashley Guthrie Austin Hatcher Foundation for Pediatric Cancer

> > **TJ Koerner** Individual Member

Susannah Koontz Speaker Coordinator Individual Member

Angela Lee National Advocacy Liaison Individual Member

Misha Mehta Neev Kolte & Brave Ronil Foundation

> Ann Ramer State Advocacy Liaison Individual Member

Aubrey Reichard-Eline With Grace Initiative

> Nicole Scobie Zoe4Life

EX OFFICIO MEMBERS OF THE BOARD

Vickie Buenger President Emeritus Individual Member

Steven L. Pessagno Treasurer/Development Lead Individual Member

Joey's Wings Foundation Julia's Grace Foundation Kiers Kidz Leia's Kids Lilabean Foundation Little Hearts of Hope LivingLFS Leukemia & Lymphoma Society MACC Fund Mattie's Miracle Cancer Foundation **MIB** Agents **Mighty Millie Foundation** Mithil Prasad Foundation Morgan Adams Foundation Mystic Force Foundation NANT-PAC Neev Kolte & Brave Ronil Foundation Neuroblastoma Children's Cancer Society Northwest Indiana Cancer Kids **Our Amazing Fighters** Pediatric Brain Tumor Foundation People Against Childhood Cancer Pine Tree Apple Classic Fund PREP4Gold **Rally Foundation** Rett's Roost Sam Day Foundation Saving Sophie Foundation Solving Kids' Cancer Swifty Foundation Team Jack Foundation The Catherine Elizabeth Blair Memorial Foundation The Grayson Foundation The Ross K. MacNeill Foundation The Scott Carter Foundation The Steven G Cancer Foundation The Taylor Matthews Foundation, a Tay-Bandz Organization This Star Won't Go Out Ty Louis Campbell Foundation Yuvaan Tiwari Foundation Zoe4Life

