



#### **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**

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Family Support This Star Won't Go Out

### Amy Godkin

ASK Childhood Cancer Foundation

# Ashley Guthrie

Austin Hatcher Foundation for Pediatric Cancer

# TJ Koerner

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## Susannah Koontz

Speaker Coordinator Individual Member

## Angela Lee

National Advocacy Liaison Individual Member

### Misha Mehta

Neev Kolte & Brave Ronil Foundation

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# EX OFFICIO MEMBERS OF THE BOARD

### Vickie Buenger

President Emeritus Individual Member

### Steven L. Pessagno

Treasurer/Development Lead Individual Member January 3, 2025

The Honorable John Thune
U.S. Senate
511 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Michael Johnson U.S. House of Representatives 568 Cannon House Office Building Washington, DC 20510 The Honorable Charles Schumer U.S. Senate 322 Hart Senate Office Building Washington, DC 20510

The Honorable Hakeem Jeffries
U.S. House of Representatives
2267 Rayburn House Office Building
Washington, DC 20510

Dear Senators Thune and Schumer and Representatives Johnson and Jeffries,

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





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

Christina Renna Foundation

CureSearch for Children's Cancer

Dana Farber Cancer Institute

Daniela Conte Foundation

Elaine Roberts Foundation



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Elevate Childhood Cancer Research and Advocacy, Inc

**End Kids Cancer** 

Evan's Victory Against Neuroblastoma Foundation

Friends of Cathyrn

Gabriella's Smile Foundation

Hope4ATRT

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



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