

Childhood Cancer Action Days 2024

Know Before you Go

Presenter: Rosie Abbott
St. Baldrick's and the Alliance for Childhood Cancer

Wednesday, January 24, 2024
1:00 pm - 2:00 pm ET



CAC2
COALITION AGAINST
CHILDHOOD CANCER



A collaborative network of organizations and individuals supporting and serving the childhood cancer community



CAC2
COALITION AGAINST
CHILDHOOD CANCER

Our Values



Respect

Enable the community while respecting our members' unique missions



Efficiency

Strive for cost effectiveness and efficiency with resources



Inclusiveness

Emphasize inclusiveness and collaboration towards our common goals



Amplify

Help give voice to the community and amplify it in a coordinated fashion



Drive

Stay action-oriented and flexible

...and always put the children and their families first in everything we do.

2023 Year in Review: Pediatric Cancer Federal Legislation

Susannah E. Koontz, PharmD, BCOP, FHOPA

Principal – Koontz Oncology Consulting LLC

Board Member At-Large – Coalition Against Childhood Cancer (CAC2)

Houston, Texas

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2023 Action Days: April 24-25

Gathered more than 200 advocates from 34 states

Consisted of 1 day of education + 1 day of visits to Capitol Hill

Advocated for robust FY2024 funding of the NIH and NCI

Sought support for full funding of the STAR Act and Childhood Cancer Data Initiative (CCDI)



2023 Action Days: April 24-25



The STAR Act



Opportunities for research

Surveillance

Quality of life for survivors

Compassionate use policies

Representation at the NIH

June 5, 2018 signed into law – Public Law No. 115-180

Childhood Cancer STAR Reauthorization Act

- In December 2022, Congress unanimously passed the Childhood Cancer STAR Reauthorization ACT of 2022 to continue for 5 more years (FY2024-2028)
 - S.4120 (117th Congress) led by Chris Van Hollen (D-MD), Jack Reed (D-RI), Shelley Moore Capito (R-WV), and Lisa Murkowski (R-AK) + 35 additional co-sponsors
 - H.R.7630 (117th Congress) led by Michael McCaul (R-TX), Jackie Speier (D-CA), G.K. Butterfield (D-NC) and Mike Kelly (R-PA) + 106 additional co-sponsors
 - Signed into law on January 5, 2023 (Public Law No. 117-350)
- During Action Days 2023, advocates pushed to appropriate \$30 million to fully fund for a 6th year

CCDI

CHILDHOOD CANCER DATA INITIATIVE

1

Gather data from every child, adolescent and young adult

2

Create a national strategy to speed diagnosis and inform treatment

3

Develop a platform/tools to bring together multiple data types to improve prevention, treatment and survivorship

During Action Days 2023, advocates pushed to appropriate \$50 million to fully fund for a 5th year

Other Select Legislation of Interest in 2023

S.1624
H.R.3391

- Gabriella Miller Kids First Research Act 2.0

S.2213
H.R.4363

- Comprehensive Cancer Survivorship Act

S.2897
H.R.3433

- Give Kids a Chance Act 2023

H.R.6664

- Innovation in Pediatric Drugs Act of 2023

Gabriella Miller Kids First Research Act

- Gabriella Miller Kids First Research Act (1.0)
 - Signed into law April 3, 2014 (Public Law No. 113-94)
 - Authorized \$12.6 million in annual funds for childhood disease research through FY2023
 - Kids First Data Resource Center
- Gabriela Miller Kids First Research Act (2.0)
 - Funding sunset in 2023
 - Re-introduction of legislation (S.1624/H.R.3391)
 - Expected to build on foundation from the last decade of discovery



Comprehensive Cancer Survivorship Act (CCSA)

- **Landmark legislation (H.R. 4363/S. 2213) re-introduced in late June 2023**
- **Aims to address gaps in research and availability of treatments and services for survivors of cancer across the continuum of their care**
- **Re-introduction of bills led by Representatives Debbie Wasserman Schultz (FL-23), Brian Fitzpatrick (PA-1) and Mark DeSaulnier (CA-10) along with Senators Amy Klobuchar (MN) and Ben Cardin (MD)**

Care Planning & Transition

Alternative Payment Model

Navigation

Quality of Care

Employment

Awareness & Education

Comprehensive Cancer Survivorship Act (CCSA)

H.R. 4363/S. 2213

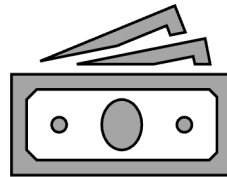


Care Planning & Transition

Provides a Medicare service and payment for care planning and coordination services

Improves coordination of care and transition to primary care

Guides survivorship monitoring and follow-up care



Alternative Payment Model

Evaluates current payment system to develop a new model to ensure coordinated survivorship services across an episode of care



Navigation

Develops comprehensive navigation services to allow for care across the continuum of survivorship

Identifies health disparities and determinants of health

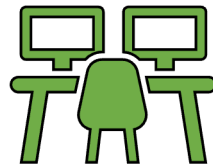
Comprehensive Cancer Survivorship Act (CCSA)

H.R. 4363/S. 2213



Quality of Care

Establishes grants to promote innovations in care to allow for more efficiencies in care delivery and improved experiences and outcomes among survivors



Employment

Establishes employment assistance grants to assist patients, caregivers and families facing a variety of workforce challenges



Awareness & Education

Creates resources for survivors and health professionals to promote early detection and preventive care
Aids health professionals in providing high-quality services

GIVE KIDS A CHANCE

Saving kids' lives at zero cost to taxpayers S 2897/HR 3433

Gives children the same chance as adults to beat cancer

Passed the House in the 117th Congress

Reintroduced in the 118th Congress

Amends the RACE for Children Act

Innovation in Pediatric Drugs Act of 2023

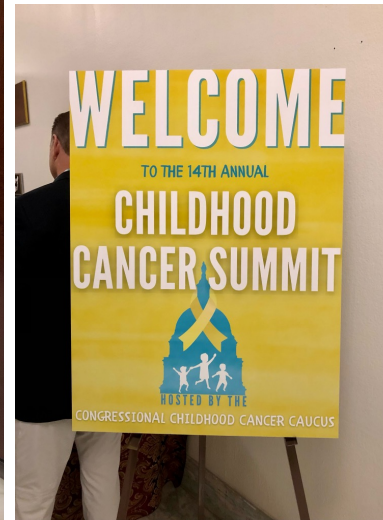
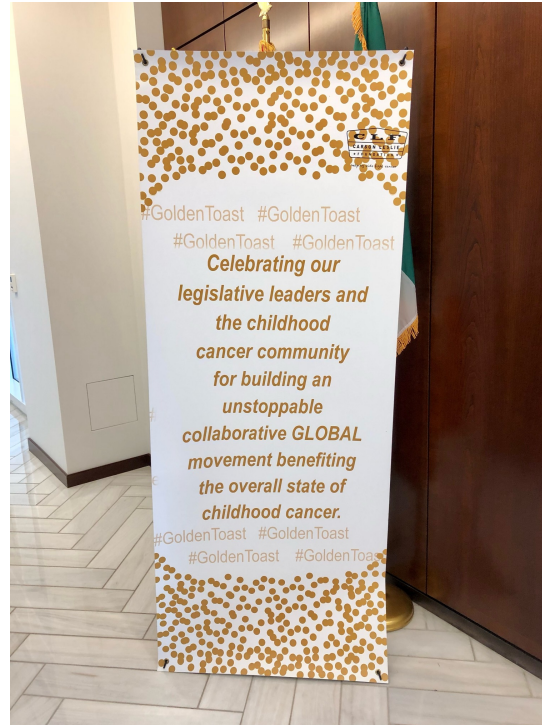
Aims to strengthen the Best Pharmaceuticals for Children Act (BPCA) and Pediatric Research Equality Act (PREA) by:

- Requiring drugs for rare diseases to be studied in children
- Granting the US FDA additional authority to penalize companies that don't complete required pediatric studies on time
- Increasing funding for the NIH BPCA Program to fund additional clinical trials and train additional personnel to help run trials

AUGUST 31, 2023

A Proclamation on National Childhood Cancer Awareness Month, 2023

 BRIEFING ROOM  PRESIDENTIAL ACTIONS



Alliance for Childhood Cancer Action Days 2024

Know Before You Go Webinar



Today's Agenda

- Action Days 2024 Agenda
- Policy Issues for Action Days
- Action Days Logistics



Action Days 2024 Agenda



Tuesday, February 13 – Morning

- Registration opens at 9:00 am
- Program begins at 10:00 am
- Guest speakers from the National Cancer Institute
- Pediatric Drug Shortages Panel
- Lunch provided at 12:00 pm



Tuesday, February 13 – Afternoon

- Program resumes at 1:00 pm
- Discussion of the policy issues and how to structure Capitol Hill meetings
- Coffee break at 2:00 pm
- Panel discussion on telling your story
- State breakout session at 3:15 pm
- Program concludes around 4:30 pm



Wednesday, February 14

- Hill Day kick-off breakfast at 7:30 am
- Group picture at the hotel
- Depart as a group and Metro to Capitol Hill
- Individual schedules provided by Advocacy Associates
- Lunch and return transportation on your own



Policy Issues for Action Days



The Asks

1) Federal Funding for Childhood Cancer Programs

In December 2022, Congress unanimously passed the Childhood Cancer STAR Reauthorization Act, allowing the programs from the STAR Act to continue for five more years.

Created in 2019, the Childhood Cancer Data Initiative to ensure that researchers learn from every child with cancer.

To continue this important work, we ask Congress to provide:

- **\$30 million** to fully fund the Childhood Cancer STAR Act for a sixth year
- **\$50 million** to fully fund the Childhood Cancer Data Initiative for a fifth year

The Asks

1a) NIH and NCI Funding

We urge Congress to provide significant funding increases for the National Institutes of Health (NIH) and a proportional increase for the National Cancer Institute (NCI).

The Asks

2) Cosponsor the Accelerating Kids' Access to Care Act (H.R. 4758/S. 2372)

Children with cancer often require specialized care from a specific provider or facility that may not be available in their home state.

Some patients face burdensome, unnecessary delays in accessing time-sensitive care, including clinical trial enrollment, outside of their home state, which can cause a child's condition to worsen.

This bill reduces regulatory burdens to allow children with complex medical needs greater access to out-of-state providers who can best meet their needs.

The Asks

3) Cosponsor the Pediatric Cancer Drug Supply Act (H.R. – For House Members Only

Drug shortages significantly impact children with cancer and the health professionals who care for them.

Providers are forced to ration key pediatric cancer drugs, delaying treatment for children and creating a disruption to clinical trials. More than half of childhood patients, survivors, and families reported experiencing a drug shortage during their treatment.

This bill creates a pilot program that directs HHS to establish and maintain a 6-month reserve of essential childhood cancer chemotherapy drugs.

Action Days Logistics



What should I plan to wear?

- Plan to wear business casual attire throughout Action Days 2024, including on Capitol Hill
- Wear your **gold gear** on Wednesday, February 14! Gold ties, scarves, jewelry, and ribbons are all encouraged. The Alliance will provide wristbands.
- Please refrain from wearing gear from your home organization
- Check the weather forecast before you pack!



Which meals are provided?

- Breakfast, lunch, and a coffee break are provided on **Tuesday, February 13**
- Breakfast is provided on **Wednesday, February 14**
- Dinner on February 13 and lunch on February 14 are on your own



What is security like on Capitol Hill?

- You will be required to go through metal detectors to enter any building on Capitol Hill. Please allow extra time ahead of your meetings to navigate security.
- Please plan to store any large bags or suitcases at your hotel on **Wednesday, February 14**, while you are on Capitol Hill



Questions?

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Thank You!

cac2.org

 @CoalitionAgainstChildhoodCancer

 @cac2org