

Childhood Cancer Awareness and Advocacy

A Review of Recent Achievements and a Look Ahead



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C. Wright Mills:

“Neither the life of an individual nor the history of
a society can be understood without
understanding both.”

Mills, C. W.: 1959, *The Sociological Imagination*, Oxford University Press, London.



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Why We Work Together



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STORIES + COLLABORATION



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Awareness Successes, 2013-2023 (abridged)

- **Community Campaigns**
 - ✓ #StepUp
 - ✓ #Cancel Childhood Cancer
 - ✓ International Childhood Cancer Day (ICCD)
- **Community Collaborations**
 - ✓ CureFest
 - ✓ Golden Toast
 - ✓ #GoldStong
- **Grassroots Awareness Efforts**
 - ✓ Lightings
 - ✓ Proclamations
 - ✓ State License Plates
 - ✓ Professional, College, and Youth Sports Teams
 - ✓ Corporate Participation in Gold Campaigns (Amazon!)
 - ✓ Community Events
- **CAC2 Efforts**
 - ✓ Childhood Cancer Fact Library
 - ✓ Childhood Cancer Event Calendar/Map



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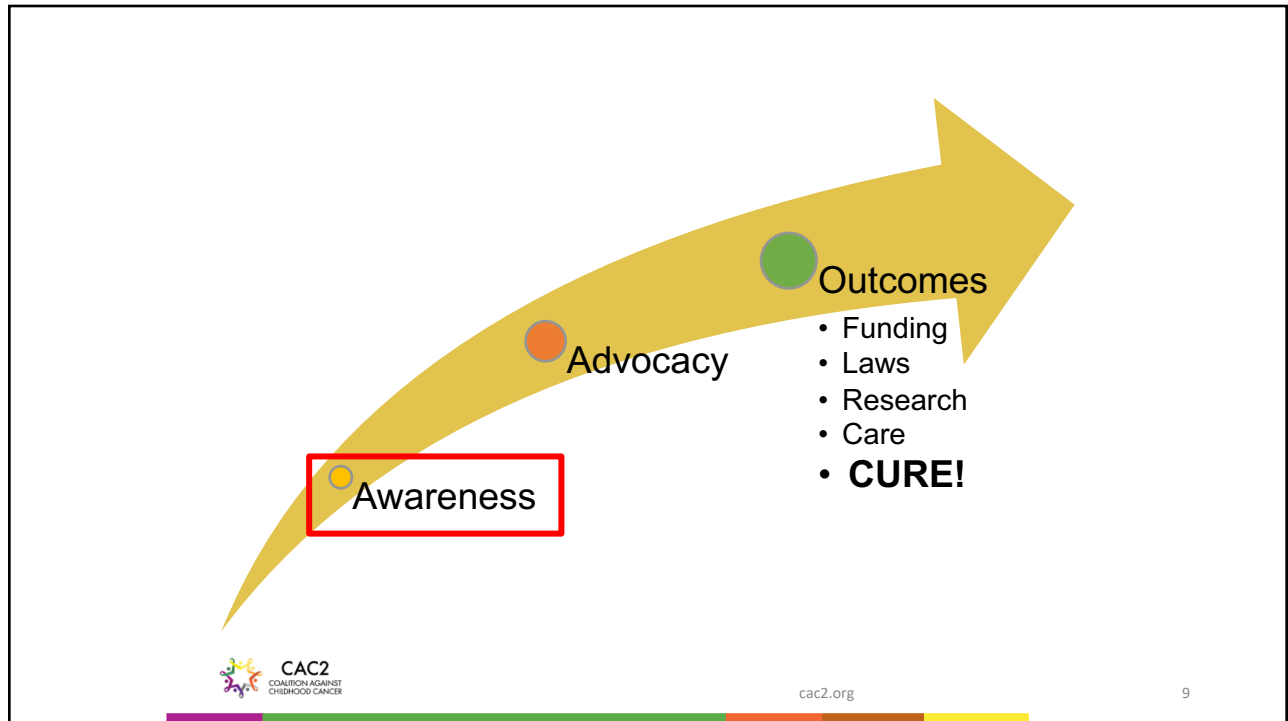
Legislative and Advocacy Successes, 2013-2023

- ✓ Indicates childhood cancer specific outcomes

- Gabriella Miller Kids First Act - April 2014 (fully funded each year 2014-22)
- ✓ Pediatric oncologist appointed to the National Cancer Advisory Board
- ✓ Reauthorization Creating Hope Act Pediatric Priority Review Voucher Act - December 2016 & 2020
- 21st Century Cures - December 2016
- ✓ RACE for Children Act - August 2017
- ✓ Appropriation language includes pediatric specific requests, 2017-present
- Children's Health Insurance Program (CHIP) renewed/extended - January 2018
- ✓ Childhood Cancer STAR Act (\$150M) - May 2018 (fully funded each year 2018-2022). Reauthorized January 2023
- ✓ Deferment for Active Cancer Treatment Act - September 2018
- ✓ Expanded eligibility categories in the Department of Defense Medical Research PRCRP for: 1) neuroblastoma, 2) pediatric and adult brain cancers, and 3) childhood cancers and adolescent and young adult cancers - 2018.
- ✓ 2019 State of the Union Address called for \$500 million in childhood cancer funding over the next 10 years. This idea became the Childhood Cancer Data Initiative (fully funded each year 2019-2022)
- Created a stand alone agency in NIH Advanced Research Projects Agency for Health (ARPA-H)
- Reignited Cancer Moonshot



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Gold Illumination

In September, the community celebrates the many efforts made throughout the community to shine awareness on childhood cancer.



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Step Up for Childhood Cancer Advocacy Campaigns a coordinated community effort that allows individuals and organizations to work together to highlight and educate decision makers and the general public about the crucial need for increased childhood cancer funding.



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#CancelChildhoodCancer – Launch Week

Chance of Getting a Hole in One
1 in 5,000
Chance of Child Getting Cancer
1 in 285

Let that sink in!

Social Media Base Established

Over 1000 people adopted the campaign FB Profile Frame in support during the first week. Dozens of organizations joined the effort.

Plans for the 8 Week Campaign

Weekly posts to call to action and build awareness

Deepen and strengthen relationships across the childhood cancer community

Culminate in multi-media event during Childhood Cancer

Launch week surpassed goal of new signatures. Multiple milestones were reached as petition accumulated over 10,000

MAKE CHILDHOOD CANCER A NATIONAL PRIORITY

1 in 285
Children will be diagnosed with cancer

#CANCELCHILDHOODCANCER
www.change.org/cancelchildhoodcancer



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CureFest Week, 2022



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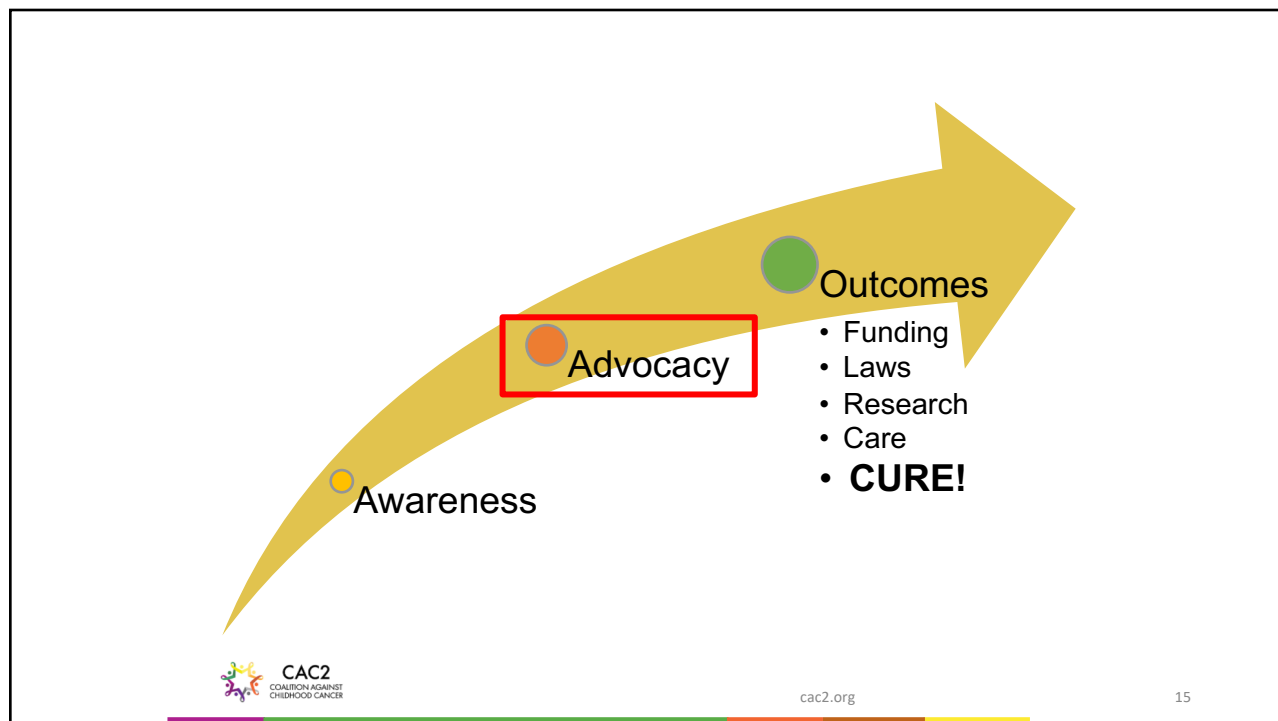
White House Cancer Moonshot: Childhood Cancer Forum



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Acknowledging Earlier Legislation

Pediatric Research Equity Act (PREA)

- 2003 – replaces the 1998 FDA pediatric rule
- Certain drugs must contain a pediatric assessment

Best Pharmaceuticals for Children's Act (BPCA)

- Signed into law in 2002 (previously FDAMA pediatric exclusivity)
- Pediatric exclusivity marketing for 6 months

Caroline Pryce Walker Conquer Childhood Cancer Act of 2007/2008


- Signed into law in 2008; re-authorization sought in 2013 and 2014
- Expanded collaborative research, improves tracking of pediatric cancers, works to identify barriers to pediatric cancer drug development and establishes new technology to aid researchers

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- Reignited Cancer Moonshot
- ✓ STAR Act Reauthorized, 2023

✓ Indicates childhood cancer specific outcomes



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Bipartisan Advocacy Wins!



Creating Hope Act
[Learn More >](#)



Childhood Cancer
STAR ACT
Survivorship Treatment Access and Research
HR 820-5292



RACE
for
Children Act



Gabriella Miller
Kids First
PEDIATRIC RESEARCH PROGRAM



CCDI
CHILDHOOD CANCER DATA INITIATIVE



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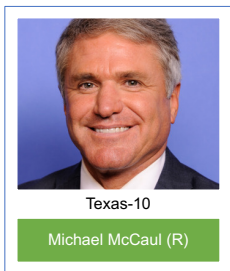
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ADVOCACY FUNDING

- 300 Million STAR Act Funding for (over ten years)
- \$500 Million Childhood Cancer Data Initiative Funding (over ten years)
- \$126 Million Gabriella Miller Kids First Act Funding (over ten years)
- \$130 Million in FY2023 Department of Defense Peer Review Cancer Research Program (PRCRP)



Congressional Childhood Cancer Caucus



4 Co-Chairs and 51 Members of the House of Representatives

Mission is to **serve as a clearinghouse for information** on pediatric cancer and a forum to **aid Members of Congress** in working together to address pediatric cancer. The Caucus will strive to **raise awareness** about pediatric cancer, **advocate in support of measures** to prevent the pain, suffering and long-term effects of childhood cancers, and **work toward the goal of eliminating cancer as a threat to all children.**

<https://childhoodcancer-mccaul.house.gov>



Childhood Cancer Caucus

Improve pediatric comprehensive cancer care and the quality of life for children and adolescents with cancer

Support increased funding for childhood cancer research through the NIH, CDC and other federal agencies

Encourage collaboration between the public sector and private research organizations to further research on pediatric cancers

Promote public policies that address the health needs of pediatric cancer survivors

Support the training of skilled cancer specialists

<https://childhoodcancer-mc caul.house.gov>



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The Alliance for Childhood Cancer

The mission of the Alliance for Childhood Cancer is to provide a forum of national patient advocacy groups and medical and scientific organizations which meets regularly, shares ideas and concerns, and works collaboratively to advance research and policies to prevent cancer, and improve public education, and the diagnosis, treatment, supportive care and survivorship of children and adolescents with cancer.



<https://www.allianceforchildhoodcancer.org>



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The Alliance for Childhood Cancer



April 25, 2023



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A Beautiful and Lasting Partnership



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Pending Legislation

- H.R. 3391/S. 1624, the Gabriella Miller Kids First Research Act 2.0
- H.R. 1780/S. 642, Finn Sawyer Access to Cancer Testing Act
- The Give Kids a Chance Act
- DIPG Pediatric Brain Cancer Awareness Day Resolution
- Appropriations Requests:
 - \$50.924 billion for NIH, an increase of \$3.47 billion
 - \$9.988 billion for NCI, an increase of \$2.668 billion
 - \$30 million to fully fund the Childhood Cancer STAR Act
 - \$50 million to fully fund the Childhood Cancer Data Initiative
 - \$130 million for Department of Defense’s Peer-Reviewed Cancer Research Program



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“Coming Soon” Legislation

- **Comprehensive Cancer Survivorship Act**
 Introduced in the House (H.R.9565) on December 14, 2022
 Companion bill in the Senate (S.5295) introduced on December 19, 2022

Care Planning and Transition	Alternative Payment Model
Navigation	Quality of Care
Workforce	Education/ Awareness

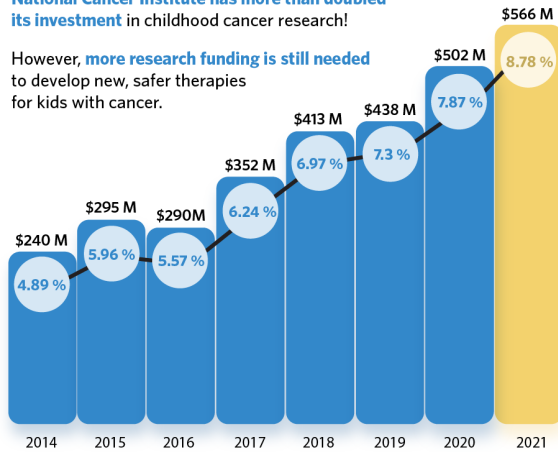


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Advocacy Works!

Thanks to greater awareness and advocacy, the **National Cancer Institute has more than doubled its investment** in childhood cancer research!

However, **more research funding is still needed** to develop new, safer therapies for kids with cancer.



Percentage reflects the share of pediatric cancer funding across total NCI obligations.



<https://www.stbaldricks.org/blog/post/advocacy-is-making-a-difference>

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What Makes the Childhood Cancer Movement Different (and Effective)?

INGREDIENT #1: Compelling Stories!

- Lived Experience
- Told with Passion



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Stories, well-told and inspiring!

SUPPORT TOUGH2GETHER AGAINST DIPG - JACE WARD RESEARCH & ACCESS FUND

#Tough2Gether

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Member Organization Namesakes

<p>Aiden Amanda Andrew Austin Bear Braden Brady Brooke Caleb Cam Carson Catherine Elizabeth Cathryn Chloe Christina</p>	<p>Connor Daniela Elaine Emily Eric Evan Gabriella Grace Jack Jack Jeremy Joey Jules Julia Kier Leia</p>	<p>Lilabeen Mattie Max Millie Mithil Morgan Myla Nora Oliver Pablo Richi Ross Ryan Ryan Sam Sammy</p>	<p>Scott Sebastian Sophia Sophie Swiftly Taylor Ty Louis Tyler Zach Zoe Zoefia Alexandria</p>
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What Makes the Childhood Cancer Movement Different (and Effective)?

Ingredient #2: Collaboration

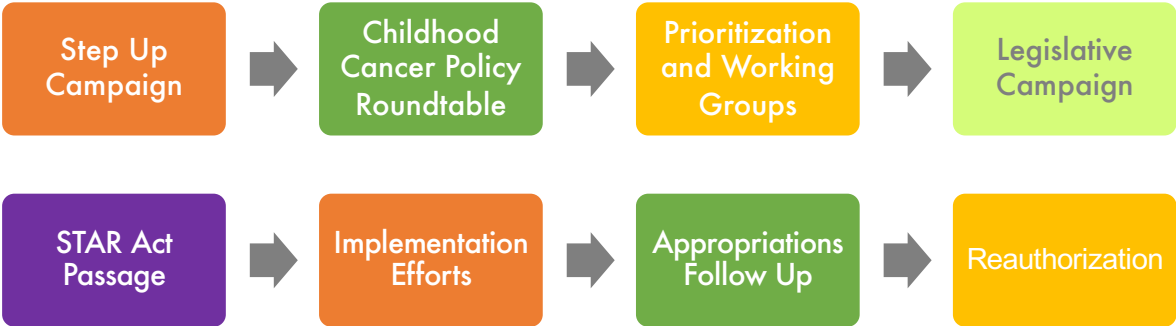
- Shared Goals
- Shared Experiences
- Prioritization Processes
- Coordinated Communication
- Cooperative Campaigns
- Inclusiveness

“Follow Up is the Chariot of Genius”




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STAR Act Deep Dive



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graph LR; A[Step Up Campaign] --> B[Childhood Cancer Policy Roundtable]; B --> C[Prioritization and Working Groups]; C --> D[Legislative Campaign]; D --> E[STAR Act Passage]; E --> F[Implementation Efforts]; F --> G[Appropriations Follow Up]; G --> H[Reauthorization]
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Our Values

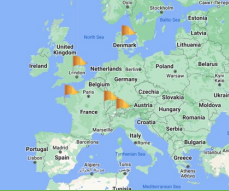

...always put the children and their families *first* in everything we do.

				
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

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CAC2 Members

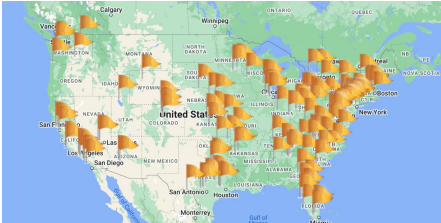
Geographical Distribution and Footprint





500 + members and associate members in 39 states and 9 countries

Together, we represent

- \$130,000,000 combined research and family support dollars
- 500,000 patients and families supported
- 1.5 million social media followers
- 1 million unique website visits
- 2 million video views/month





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CONTINUING CHALLENGES WE STILL HAVE WORK TO DO!

- Lack of Progress Globally
- Heavy Burden of Treatment for 500,000 Survivors
- Financial Toxicity
- Environmental Exposure to Cancer Causing
- Treatment Gaps



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WE HAVE TO HAVE HOPE!



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Working together today for a future without childhood cancers



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