



Spring All-Member Webinar

March 20, 2024



CAC2
COALITION AGAINST
CHILDHOOD CANCER



Agenda

Welcome

Our Impact Program Collaboration Highlights

Our Community Be a part of it!

- Board Nominations and Volunteer Needs
- Opportunities to Connect

Our Future

- Organization Updates
- Where do we go next?



Our Values

We put 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



CAC2 Patient Advocacy Industry Relationships (PAIR) Workshop

October 10, 2023 | Ottawa, Canada



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The PAIR Project

NAME	TITLE AND ORGANIZATION	ASSOCIATION
Caitlyn Barrett	Board Member	Coalition Against Childhood Cancer (CAC2)
Vickie Buenger	President Emeritus	Coalition Against Childhood Cancer (CAC2)
Ann Graham	Founder and Executive Director	MIB Agents Osteosarcoma
Christa Kerkorian	Vice President of Patient Advocacy	Day One
Gavin Lindberg	President & Co-Founder	The EVAN Foundation
Donna Ludwinski	Director of Research Programs	Solving Kids' Cancer US
Joe McDonough	President	The Andrew McDonough B+ (Be Positive) Foundation
Gwen Nichols	Chief Medical Officer	The Leukemia & Lymphoma Society
Vasiliki Rahimzadeh	Assistant Professor, Medical Ethics and Health Policy	Baylor College of Medicine
Samantha Reyes	Patient Engagement Lead: Pediatric Cancer/Neurology	Sanofi
Cesare Spadoni	Founder & Chief Operating Officer	Oncoheroes Biosciences
Amy Weinstein	National Director of Research Investments and Advocacy	Pediatric Brain Tumor Foundation

Sponsors also included United Therapeutics, Jazz Pharmaceuticals and AstraZeneca; however, they could not attend the workshop in person.



CAC2 Survivorship Tool Kit

**Co-led by Mariah Forster Olson, Neuroblastoma Children's Cancer Society
and Mary Beth Collins, Individual Member**

- Dena Sherwood, Arms Wide Open Childhood Cancer Fdn
- Alma Morgan, ASK Childhood Cancer Foundation
- Stacia Wagner, Children's Brain Tumor Foundation
- Steve Wosahla and Julie Taylor, Children's Cancer Cause
- Joao Braganca, past member of Childhood Cancer International
- Kelli Wright, Day One Biopharmaceuticals
- Jeremy Bliler, Gold Rush Cure Foundation
- Sarah Lilly, The Lilabeau Fdn for Pediatric Cancer Research
- Cheryl Yasis, Pine Tree Apple Classic Fund
- Erika Carson, The Brain Bodega
- Simon Strong, The Oliver Foundation
- Jenn Kelley, Pediatric Brain Tumor Foundation
- Kathy Riley, past member Pediatric Brain Tumor Fdn
- Dave Achey, Wit You Against Childhood Cancer
- Carolyn Breinich, Individual Member
- Vickie Buenger, Individual Member
- Judy Fulmer, Individual Member
- Shannon Hartey, Individual Number
- Lysi Kinyon, Individual Member
- Angela Lee, Individual Member
- Glynnis McDonnell, Individual Member
- Rachel McCallum, Individual Member
- Juanita Prada, Individual Member
- Ann Ramer, Individual Member
- Sarah Ross, Individual Member
- Ellen Shoheit, Individual Member





CAC2 Survivorship Tool Kit cont'd

A special thank you to:

- St. Jude Children's Research Hospital, Dr. Melissa Hudson, Dr. Daniel Mulrooney, and Dr. Greg Armstrong for providing the Foreword
- Survivors Juanita Prada and Joshua Hofmeister for the creation of the introduction video
- Julie Taylor for her significant contribution to the CAC2 Survivorship Toolkit Launch
- CAC2 leadership and staff for their support

Financial and In-Kind Support:

The Neuroblastoma Children's Cancer Society

Sobah Systems

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>



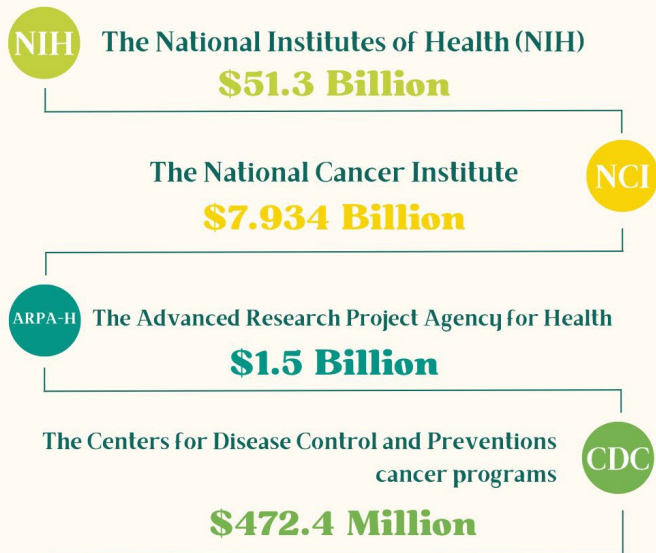


2024 Action Days



Federal Funding for Pediatric Cancer

OVAC FY25 REQUESTS



<https://x.com/ovacinfo/status/1765036359943585806?s=46&t=3baZ6Gf53Shv2ljXhayVtg>



STAR Act Funding

- 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 2024, advocates pushed to appropriate \$30 million to fully fund for a 7th year

<https://www.vanhollen.senate.gov/news/press-releases/childhood-cancer-star-reauthorization-act-signed-into-law>



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 2024, advocates pushed to appropriate \$50 million to fully fund for a 6th year



Accelerating Kids' Access to Care Act H.R. 4758/S. 2372

- Creates a new pathway for pediatric providers to enroll in multiple state Medicaid programs if certain requirements are met
- Focuses on the screening and enrollment of providers and
 - NOT on authorization of care by an out-of-state provider
 - NOR payment rates for any such care
- Introduced on July 19, 2023
 - House by Lori Trahan (D-MA) and Mariannette Miller-Meeks (R-IA)
 - 81 co-sponsors to date
 - Senate by Chuck Grassley (R-IA) and Michael Bennet (D-CO)
 - 35 co-sponsors to date

1. <https://www.childrenshospitals.org/content/public-policy/talking-point/cosponsor-the-accelerating-kids-access-to-care-act>
2. <https://www.congress.gov/bill/118th-congress/house-bill/4758/cosponsors>
3. <https://www.congress.gov/bill/118th-congress/senate-bill/2372?q=%7B%22search%22%3A%22S.2372%22%7D&s=1&r=1>



Pediatric Cancer Drug Supply Act (H.R. 6963)

- Drug shortages are increasingly becoming more common and significantly impact patients and healthcare providers alike
 - Forces prioritizing treatments among patients
 - Disrupts clinical trials as well as delays care
- Creates a pilot program
 - Directs HHS to maintain a 6-month reserve of essential chemotherapy medicines for childhood cancer
- Bill introduced in the House on January 11, 2024 by Anna Eshoo (D-CA), Diana DeGette (D-CO) and Kim Schrier (D-WA)
 - 15 co-sponsors to date

1. <https://eshoo.house.gov/media/press-releases/rep-eshoo-degette-schrier-introduce-bill-ensure-stable-supply-pediatric>
2. <https://www.congress.gov/bills/118th-congress/house-bill/6963/cosponsors?s=4&r=1&q=%7B%22search%22%3A%22H.R.6963%22%7D>



Advocate



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Pending Federal Legislation – Take Action

H.R. 4758/S. 2372, Accelerating Kids' Access to Care Act (AKACA) — Cancer care for children is not always available close to home, which means many families must travel to other states for treatment. Accessing care in other states is time consuming and challenging to navigate. This legislation would improve children's access to needed out-of-state health care by streamlining the Medicaid provider screening and enrollment process.

You can read more about the bill here: [AKACA](#)

<https://cac2.org/impact-areas/advocacy/take-action/>





Volunteer Needs and Board Nomination Process



Volunteer Needs

- **Event Planning**
 - 2025 Annual Summit
 - 2026 Annual Summit
 - 2024 CureFest Reception with Alliance for Childhood Cancer
 - Regional meet-ups
- **Assistance with Webinars** (especially tech expertise)
- **Advocacy Drop-in Host**
- **Membership Lead**
- **Childhood Cancer Fact Librarian**
- **Communications Lead** (responsibilities can be split)
 - social media
 - awareness
 - general communications

Current Board Members

Robin French*, **Board Chair**
The Morgan Adams Foundation

Amy Godkin*, **Immediate Past Chair**
ASK Childhood Cancer Foundation

Ginny McLean*, **Vice Chair**
Swiftly Foundation/Gift from a Child

Mariah Forster Olson*, **Secretary & Survivorship Liaison**
Neuroblastoma Children's Cancer Society

Caitlyn Barrett*, **Research Liaison**
Milkin institute

Steve Pessagno**, **Treasurer & Development Lead**
Individual Member

Lori Earl, **Family Support Liaison**
This Star Won't Go Out

Susannah Koontz, **Speaker Coordinator**
Individual Member

Angela Lee, **National Advocacy Liaison**
Individual Member

Ann Ramer, **State Advocacy Liaison**
Individual Member

Amy Weinstein, **Past Board Chair**
Pediatric Brain Tumor Foundation

Vickie Buenger**, **President Emeritus**
Individual Member

** ex officio * Executive Committee



Nomination and Voting Process

- In April and May, the CAC2 Board of Directors will assess nominations for this year's annual election of the Board of Directors.
- Candidates selected for the slate will be announced in the CAC2 June Announcements.
- Voting will be conducted during the CAC2 members' business meeting.
- Only individual Members and the Voting Representative from Childhood Cancer Organization Members are eligible to vote.
- Written voting proxies are allowed for members not present at the members' business meeting in June.
- Each CAC2 member entitled to vote shall indicate support for or opposition to the slate of nominees.

CAC2 Nomination Principles

- First-term board members have the option to stand for re- election at the end of their terms for a 2nd consecutive 3- year term.
- CAC2 Board is a working board (no paid positions), making it important to assemble a diverse set of backgrounds and skills to set and implement an effective strategy for the Coalition, its members, and the kids and families the CAC2 membership serve.

If you are interested in Board service, please email Robin French:
robin@morganadamsfoundation.org

Opportunities to Connect



Opportunities to Connect

- Family Support Drop-Ins
- Providers of Bereavement Support Drop-In
- Advocacy Drop in
- Innovation Council
- Webinars
- Regional Meet Ups
- CureFest CAC2/Alliance Gathering
- 2024 Virtual Business Meeting
- 2025 Annual Summit

CAC2 All Member Webinar

2024 CAC2 Webinar Series

Susannah E. Koontz, PharmD, BCOP, FHOPA
Houston, TX



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2024 CAC2 Webinar Series

- Planning 6-9 programs throughout 2024
- Objectives
 - Provide education related to childhood cancer which is representative of CAC2's pillars
 - Build relationships among stakeholders working to end childhood cancer
 - Increase awareness of CAC2 as an organization

2024 CAC2 Webinar Series

- Webinar announcements with descriptions and sign-up will be distributed in the monthly CAC2 member e-mail update and on social media
- If you have an idea or suggestion:
 - E-mail Susannah Koontz at susannahrx@gmail.com
 - CAC2 website <https://cac2.org/about/who-we-are/contact-us/>

CAC2 Innovation Council

Invitation to Engage!

- Opt-In to receive early information about opportunities pitched to CAC2.
- Recent Examples?
 - App to support home physical therapy for children with cancer
 - Micro-donation fundraising platform for families and foundations
 - ArtVsCancer, artists who create free custom art for children with a life-threatening illness
 - Initiative to expand access to early phase trials/CAR-T and/or provide family resources to participate in such trials
- How do members benefit?
 - Early access to ideas and developing opportunities
 - Chance to provide feedback and request additional information
- Who? **Everybody!**



All Member Meet-up! Join Us During ISPNO

Cohosted By
Children's Brain Tumor Network (CBTN)
Pacific Pediatric Neuro-Oncology Consortium (PNOC)

June 29, 2024 | Philadelphia, PA



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Our Host

2025 CAC2 Annual Summit at Children's National Hospital Innovation Campus

June 2025
Washington, D.C.



Organization Update

Staffing and Leadership Update

The CAC2 Board of Directors voted to pursue an Association Management Company rather than directly paid staff positions

Benefits of Association Management Model

- Access to resources, expertise and experience on multiple
- Roles are filled as needed- with appropriate expertise
- Capacity to grow or transition off as organization matures and evolves
- Consistent management as board continues to rotate through terms

Staffing and Leadership Update

Status of Search

Timeline for Transition to Association Management

- 10 RFPs were emailed in February
- 3 AMCs have expressed interest/ 2 have submitted proposals
- Search Working Group (SWG) is currently evaluating proposals
- SWG meets to discuss and provide recommendation to board w/o 3/24
- Board Approval by 4/1
- Final Negotiations with AMC
- Transition timeline and oversight committee established 4/15

Coalition Against Childhood Cancer (CAC2)

Opportunities for Partnership



cac2.org



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About the Coalition Against Childhood Cancer

Let's imagine
a world without
childhood
cancers.

CAC2 is a **collaborative network** of nonprofits, corporations, associations, and individuals from **43 states** and **9 countries**, supporting and serving the childhood cancer community.

CAC2 members effectively advance a variety of childhood cancer causes by **unifying their efforts**.



CAC2's Mission

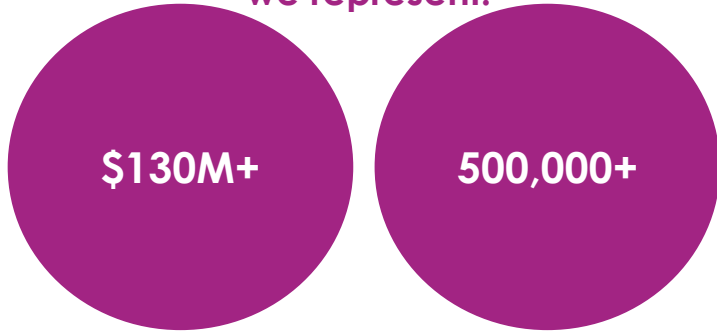
The mission of the Coalition Against Childhood Cancer (CAC2) is to foster and sustain greater levels of **collaboration, information exchange, and learning across the childhood cancer community** through agreed upon initiatives in the areas of **advocacy & awareness building, family support, survivorship, and research & treatment.**



Impact and Reach

CAC2 membership is comprised of more than 500 members and associate members, all passionate about changing – and ultimately improving – the lives and treatment outcomes for the 17,000 children and teenagers who will be diagnosed with cancer this year.

Together,
we represent:



total support dollars for the
pediatric and AYA cancer
communities

patients and families
served

Through community
outreach, we have:



1.5M+
social
media
followers

1M+
unique,
collective
website
visits

2M
member
video
views per
month

The Collective

CAC2 effectively advances a variety of childhood cancer causes by **unifying the childhood cancer community** through educational efforts and by creating processes to help us choose, refine, and complete collaborative projects together.

CAC2 offers childhood cancer patients, survivors, and their families a “**one-stop**” source of information and brings together professionals and advocates working to accelerate advances in pediatric cancer research to discover new and better treatments – and, ultimately, cures.



CAC2 is “10 for 10” on its collaborative projects!

In Process

- 1) **Foundation Match for Joint Research Funding:** <https://cac2.org/impact-areas/research-treatment/foundation-match/>
- 2) **Better Together: Survivorship Connection:** <https://cac2.org/impact-areas/survivorship/better-together/>

Ongoing

- 3) **Hope Portal:** <http://hopeportal.org/>
- 4) **ICRP:** <https://cac2.org/interest-groups/research-treatment/icrp/>
- 5) **Childhood Cancer Fact Library:** cac2.org/childhood-cancer-fact-library
- 6) **CureFest:** curefestusa.org
- 7) **Evergreen Event Map-Calendar:** <https://cac2.org/events/>
- 8) **Gold Awareness:** cac2.org/gold-awareness-project
- 9) **Ethics Think Tank:** <https://cac2.org/impact-areas/research-treatment/ethics-think-tank/>

Completed

- 10) **Bench to Bedside and Beyond Pediatric Cancer Research Conference:** https://cac2.org/wp-content/uploads/2020/07/2016-CSHL-CAC2_Conf_Proceedings.pdf

You Are the Difference!

Your support will make the difference for the **47 children and teens who are diagnosed each day*** with 1 of 12+ major childhood cancers, the **tens of thousands of families** who have a child currently in treatment, the **families who have lost a child**, and the **hundreds of thousands of pediatric cancer survivors** who experiences lifelong, chronic health related issues.

*Approximately 1 in 285 children in the U.S. will be diagnosed with cancer before their 20th birthday.



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- **Increase your visibility and raise awareness for your organization** through sponsor benefits, co-branding, and donor recognition
- **Be part of the conversation with more than 500 representatives** of the childhood cancer community
- **Meet and connect with pediatric and adolescent cancer advocates**, change-agents, funders, and community leaders
- **Support a national collaborative initiative** that exists for one sole purpose – to support and serve the childhood cancer community

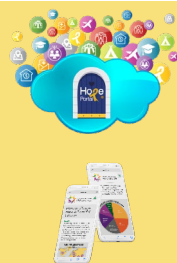
CAC2 Sponsorship Opportunities

Contact CAC2 to learn more about sponsorships that support our mission and member-driven initiatives. Event and project sponsorships include:



Welcome Reception at CureFest in Washington, DC

Advancing CAC2's work to **raise public awareness** about pediatric cancer, honoring patients and survivors, and celebrating Childhood Cancer Awareness Month



Hope Portal: A **searchable database** that connects pediatric, adolescent, and young adult cancer families and survivors to organizations that offer a vast array of critical resources, services, and information

ICRP: A unique alliance of cancer research organizations that shares funding information to **enhance global collaboration and strategic coordination of research** between individual researchers and organizations

Collaborative Projects: Survivorship










Webinar Series

Creating a **forum for unique information-sharing** and opportunities to learn from experts and from each other

Thank You to Our 2023-24 Sponsors

Annual Collaborative Projects

Catalyst Sponsorship	Sponsor(s)	
2023 CAC2 Welcome Reception at CureFest	AstraZeneca	
Hope Portal	Day One Biopharmaceuticals	
	Jazz Pharmaceuticals	
Better Together: Survivorship Connection	The Neuroblastoma Children's Cancer Society	
Childhood Cancer Fact Library	SebastianStrong Foundation	
Foundation Match	Focused Ultrasound Foundation	
Survivorship Toolkit	The Neuroblastoma Children's Cancer Society	

Thank You to Our 2023-24 Sponsors

PAIR Project: Patient Advocacy Industry Relations



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ONCOHEROES
BIOSCIENCES



2024-25 Sponsorship Opportunities

Collaborative Projects

Opportunity	Amount
Welcome Reception at ISPNO Philadelphia: June 28, 2024	TBC
Welcome Reception at CureFest Washington, DC: September 20, 2024	AstraZeneca 
Childhood Cancer Hub	\$ 10,000
Hope Portal + Better Together: Survivorship Connection (BT:SC)	AstraZeneca 
Webinar Series	\$ 10,000
2024 Members' Business Meeting (virtual) – Presenting Sponsor	\$ 5,000

Opportunity	Amount
ICRP Database	AstraZeneca 
Childhood Cancer Events Map	\$ 2,500
Childhood Cancer Fact Library	\$ 2,500
Survivorship Toolkit	\$ 2,500
2024 Volunteer of the Year Award	\$ 1,000
2024 Members' Business Meeting (virtual) – Supporting Sponsors	\$ 1,000

Invest in Capacity-Building

In its 11th operating year, CAC2's mission continues to be vital to the childhood cancer community, its members' passion and commitment is unwavering, and member-driven collaborations continue to increase our impact and reach.

CAC2 is an established and thriving organization that requires charitable and sponsorship support (in addition to revenue from membership dues) to continue to achieve our mission today and to build capacity and support growth for years to come.

Let's imagine our future together working for a world without childhood cancers. Thank you for your support of CAC2!



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CAC2 2024 Sponsorship Opportunities

Capacity Building

	Organizational (“Global”) Sponsorships <i>Investing in CAC2’s mission and collaborative work towards a future without childhood cancers</i>			Catalyst Fund Sponsorships <i>Investing in member-driven initiatives and Board-approved activities that advance CAC2’s mission</i>	
	Gold Ribbon Hero	Champion Sponsor	Sustaining Sponsor	Unity Sponsor	Care Sponsor
Sponsorship Amount	\$100,000	\$75,000	\$50,000	\$25,000	\$15,000
Recognition in CAC2 Publications	✓	✓	✓	✓	✓
Recognition on CAC2 Website	✓✓	✓✓	✓✓	✓	✓
Co-Branding Opportunities	✓✓✓	✓✓	✓	✓	✓
Recognition and Brief Remarks at Annual Members’ Meeting	✓✓	✓	✓	✓	
Recognition during Welcome Remarks for each CAC2 Webinar	✓				
Remarks at In-Person CAC2 Events	✓				

Benefits for all CAC2 sponsorship levels:

Your logo on the CAC2 website in the *Who Makes It Possible* webpages

Recognized as a CAC2 sponsor and partner in 1 monthly eNewsletter

Name in Philanthropy Listing in CAC2 FY24 Annual Report
(must be committed by June 30, 2024)

All sponsors will also receive unique promotional benefits related to the sponsored event or initiative.



Support CAC2 today

Contact Steven L. Pessagno, CAC2 Treasurer, to get started or learn more:
admin@cac2.org | 215-888-6524



[@CoalitionAgainstChildhoodCancer](https://www.facebook.com/CoalitionAgainstChildhoodCancer)



[@cac2org](https://twitter.com/cac2org)



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[cac2.org](https://www.cac2.org)

We want to hear from CAC2
Members – Move to Break out Rooms

We want to hear from CAC2 Members –
Report out from Break out Rooms

Thank You!

cac2.org

 @CoalitionAgainstChildhoodCancer

 @cac2org

48