



2019-2020 ANNUAL REPORT



CAC2
Coalition Against Childhood Cancer

CAC2.org

A photograph of two young children, a boy and a girl, sitting on a light-colored wooden floor. They are surrounded by various toys, including colorful wooden blocks, alphabet letters, numbers, and a small toy train on a track. The boy is wearing a white t-shirt and blue shorts, and the girl is wearing a white lace-trimmed top and green shorts. They are both focused on their play. The image is overlaid with a semi-transparent orange filter.

Working together today for a future without childhood cancers

CAC2 effectively advances a variety of childhood cancer causes by unifying the childhood cancer community through broad-based coordinated action and collaboration that leverages the strengths and expertise of its members and minimizes duplication of effort.

Contents

President’s Message	4
About CAC2	5
Mission	6
Leadership	7
Treasurer’s Report	8
Supporters	12
Childhood Cancer Facts	15
Membership	16
Join Us	18
Impact	19
Collaborative Spotlight	20
Activity Highlights	22
Webinars	26
2019 Summit and Members’ Meeting	28
International Cancer Research Partnership (ICRP)	30
Hope Portal	31

PRESIDENT'S MESSAGE

Members and Friends,

I'd like to welcome our new members. In the last year, 12 new Childhood Cancer Member Organizations, 14 new Individual Members, six new Student Members, and four new Supporting Organizations joined CAC2. I'd also like to thank our faithful renewing members! Together we have accomplished much, and in 2020, we need each other more than ever.

CAC2 strives to bring together the many organizations and individuals from the childhood cancer community to collaborate on activities and initiatives within our foundational pillars: Awareness & Advocacy, Family & Survivorship Support, and Research & Treatment. We have worked together over the past year to build and strengthen initiatives in each of these areas and to reinforce our efforts to serve our community through education and outreach. Supporting our members remains the common thread in everything we do, and we have launched several new initiatives to spotlight, engage, and connect our members.

Throughout the pages of this year's Annual Report you will find valuable information about more than a dozen ongoing CAC2 initiatives. We are especially proud of the recently updated Childhood Cancer Fact Library, the constantly growing and improving Hope Portal, our CAC2 Webinar Series covering the most interesting and pressing topics of our times, and the work we have done in cooperation with the International Cancer Research Partnership to build a more complete picture of childhood cancer research funding throughout the world.

I'd also like to guide your attention to some of our newer efforts. We showcase our members through newsworthy blog entries and by showcasing the published works of our members on Books by Members on CAC2.org. We have provided both training and opportunity to members so they can contribute to national discussions around topics as disparate as drug shortages, RACE Act implementation, and the redesign of ClinicalTrials.gov. We seized the opportunity to support our members even more directly this year by maintaining a compendium of resources called the CAC2 Member Guide to Navigating the Covid-19 Crisis and by planning and carrying out #GivingTuesdayNow, an outreach effort to encourage others to volunteer and donate to our Childhood Cancer Member Organizations.

Ending our operating year is not the same as bringing an end to the stresses and disruptions we are all experiencing. The pandemic and accompanying economic downturn have threatened nonprofits around the world, including our members. Yet every day, our members demonstrate resilience and creativity as they strive to make up fundraising shortfalls and fulfill their commitment to funding meaningful research and supporting families in need. CAC2 pledges to stand with its members and identify ways to leverage scarce resources and ease our members' search for the information they need and the collaborative opportunities they want.

In these unprecedented times, all I know for sure is that children and teens with cancer, their families, and the wider community of survivors need us, and we are stronger when we stick together. Thank you for your trust and partnership.

With everlasting appreciation,



ABOUT US



CAC2 exists to ensure that the childhood cancer community benefits from greater levels of coordinated action and collaboration. Our nearly 200 organizational, individual, and student members care greatly about and invest themselves in making an impact on childhood cancer.

We organize our initiatives and programs around three basic pillars of interest that our members share: Awareness & Advocacy Support, Research & Treatment, and Family Support & Survivorship. We work to share information with and among our members and to provide numerous opportunities for education within each pillar. We also facilitate coordinated action, broad-based collaboration, and shared projects among our members.

We rely primarily on the time, skills, and energy volunteered by our members to undertake initiatives that foster and sustain greater collaboration across the childhood cancer community. While our members fund research and support families directly, CAC2 does not. Instead, CAC2 focuses on activities that cannot be effectively and efficiently delivered in the absence of coordinated action.

Our members may operate celebratory or legacy foundations in honor or memory of a special child or adolescent affected by cancer. They may have devoted their personal or professional lives to working for children with cancer. They may have survived childhood cancer themselves. Or they may just feel a close, personal connection to the cause. What unites us all is the belief that the increased impact created and amplified by collaboration will drive progress for childhood and adolescent cancer patients. Together we work with a burning passion and unrelenting energy to improve their lives and the lives of their families.



CAC2 is a collaborative network of organizations and individuals supporting and serving the childhood cancer community.



We envision a world without childhood cancers.

MISSION

CAC2 fosters and sustains 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 & Survivorship Support, and Research & Treatment.

The primary values underlying CAC2 are to put the children and their families first in everything we do and to support organizations active in the fight against childhood cancer. We support our members and the childhood cancer community through action-oriented, member-directed projects and a variety of educational outreach initiatives.



We work together so that one day, no child will die of cancer and all survivors may thrive and prosper.



LEADERSHIP

Vickie Buenger, President
Independent Advocate

Kim Buff, Membership Lead
Momcology

Donna Criner, Development Co-Lead
Northwest Indiana Cancer Kids Foundation

Angie Giallourakis, Family Support Interest Group Liaison
Steven G. AYA Cancer Research Fund

Jess Kean, Communication Lead & Advocacy Group Liaison
Children's Cancer Cause

Ginger Diamond, Vice President and Meetings Lead
Childhood Cancer Awareness Group of Coffee County

Kyle Matthews, Secretary and Technology Lead
Beat Childhood Cancer

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

Steven L. Pessagno, Treasurer & Development Co-Lead
Independent Advocate

Tom Pilko, Nominating Chair
Independent Advocate

Neal Rourke, Awareness Group Liaison
Independent Advocate

Julie Sutherland, Marketing and Materials Lead
Make Some Noise: Cure Kids Cancer Foundation

Amy Weinstein, Assistant Secretary & Research Interest Group Lead
Pediatric Brain Tumor Foundation



TREASURER'S REPORT

CAC2 began its seventh Fiscal Year (FY7) on July 1, 2019 in a strong financial position given its expected plans for the second half of 2019 and the first half of 2020. We're fortunate to have ended FY7 (on June 30, 2020) on equally strong footing, especially given how the coronavirus pandemic has upended society in so many ways – for individuals, families, communities, organizations, corporations, and governments alike. The world of childhood cancer is not immune to the myriad pandemic-induced disruptions – which is why it's even more important that childhood cancer stakeholders work together and focus on the priorities that are most likely to have near-term positive impact on pediatric cancer patients and survivors as well as their families, support systems, health care professionals, and the researchers working to discover improved treatments and hopefully cures.

The momentum within the childhood cancer community in general, and for CAC2 in particular, was palpably strong since last July – until the coronavirus pandemic stopped us in our tracks. This is one reason why Fiscal Year 8 (FY8) is so pivotal for CAC2 and its members. Pediatric cancer diagnoses and survivorship issues are not slowing down, and neither shall we.

FY8 is also pivotal for CAC2 for a different reason: leadership succession planning. At the June 2021 Annual Summit, our President, Vickie Buenger, will reach the limit of her Board service. Through Vickie's stewardship, the leadership of the Board of Directors, and the collaborative work of its members, CAC2 has grown in membership and importance to the childhood cancer community. To position CAC2 successfully for sustainability for years to come, the Board of Directors has proposed a transition plan that eliminates the position of President and divides the President's current duties and responsibilities between a volunteer Chairperson of the Board of Directors and a paid Managing Director position. This structure represents a common governance arrangement for non-profits similar to CAC2. In practice, this

will require CAC2 to increase its current budget for operating expenses from \$100,000 to \$175,000-\$200,000. This would be significant for CAC2 even if we were not in the middle of a pandemic, because CAC2 seeks donations and grants to fund its operations in a way that does not compete with our Childhood Cancer Member Organizations' mission-driven fundraising. Therefore, we will be seeking out partnerships that will enable CAC2 to thrive beyond the leadership transition that will occur in June 2021. For now, please refer to the figures on the following pages for a snapshot of FY7 financial performance for CAC2.

CAC2 OPERATING BUDGET PLAN
FY: July 1, 2019 - June 30, 2020

Target	Actual	% of Target	
\$ (122,500.00)	\$ (90,478.31)		EXPENSES
	\$ (285.00)		FEES: Authorize.net
	\$ (58.21)		FEES: Cybersource
	\$ (1,056.58)		FEES: ACH Settlement
	\$ (26.00)		FEES: PNC Bank
	\$ (152.56)		FEES: Network for Good, PayPal, Pledgling
	\$ (92,056.66)	75%	OPERATING EXPENSES
\$ 10,000.00	\$ 23,300.00	233%	MEMBERSHIPS: New
\$ 44,720.00	\$ 53,650.00	120%	MEMBERSHIPS: Renewals
\$ 85,000.00	\$ 42,641.22	50%	DONATIONS and GRANTS
\$ 139,720.00	\$ 119,591.22	86%	REVENUE
	\$ 27,534.56		NET INCOME

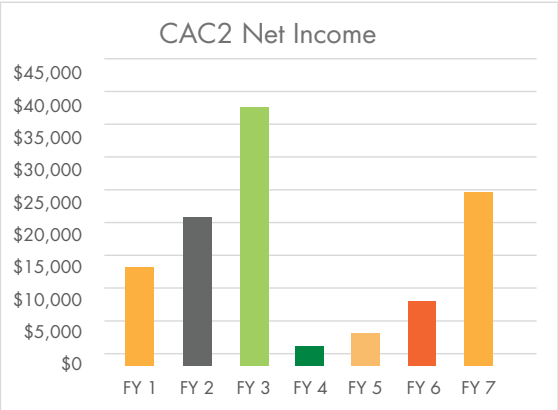
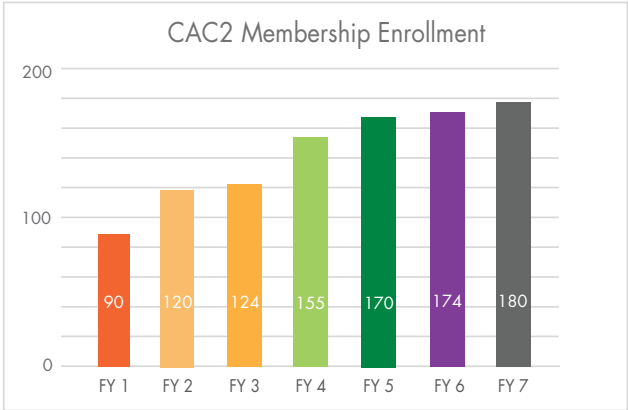
As always, we thank everyone who has believed in CAC2 throughout its first seven years and has enabled our membership to achieve "7 for 7" in delivering projects in our foundational pillars of Awareness & Advocacy, Family Support & Survivorship, and Research & Treatment. We look forward to helping shape a bright future for childhood cancer patients, survivors, and their families through powerful ideas, teamwork, and even greater levels of support.

Steven L. Pessagno
Treasurer, Coalition Against Childhood Cancer

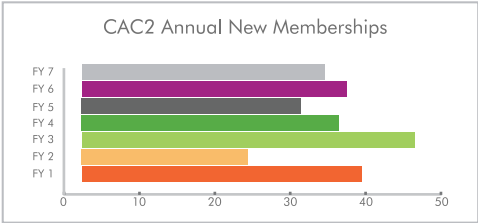
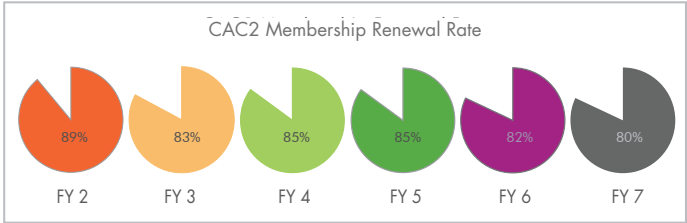




TREASURER’S REPORT - CONTINUED



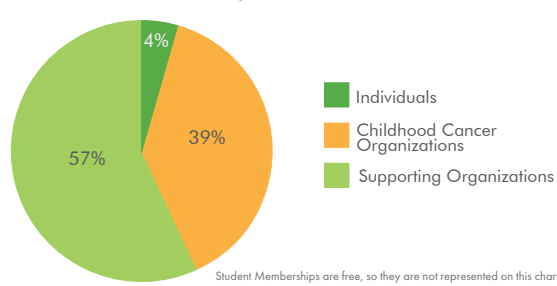
CAC2 was incorporated as a membership organization. We continue to enjoy a growing membership enrollment, which fuels both our operating budget and our manpower. As we are not a fundraising organization, we rely heavily on membership dues to meet our expenses. Renewal rates remain consistent, and our small attrition rate is due primarily to changed circumstances of our members.



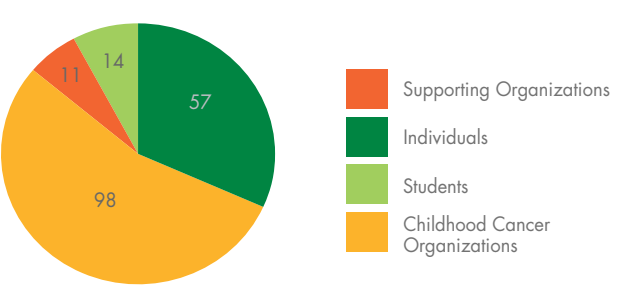
Membership is a staple of our revenue, but gifts and grants are also an integral part of our operating budget. Please refer to pages 12-13 in this Annual Report for a listing of all the companies, individuals, and organizations that provided donations and grants to CAC2 this year.

Our partners inspire CAC2 to aim higher, strive harder, and dream bigger about what we can accomplish on behalf of the children, adolescents, and families who are impacted by pediatric cancers.

CAC2 Membership Revenue Distribution



Membership Type Distribution



43%

While Student, Individual, and Childhood Cancer Organizational Members combined to make up less than half the annual CAC2 membership revenue, it is tremendously important to acknowledge these members as 100% of the volunteer workforce at CAC2. Our members deliver the passion and commitment that drives the CAC2 mission forward each and every day for the children, AYA, survivors, and families affected by childhood cancer.

57%

Equally important to acknowledge are the Supporting Organization Members whose combined dues make up more than half of our membership revenue. Our Supporting Organization Members play a critical role in affording CAC2 the opportunity to fulfill its mission and create an ever-increasing impact on the childhood cancer community. CAC2 is very grateful for these generous supporters of our mission.

SUPPORT



CAC2 extends heartfelt gratitude to the individuals, organizations, and companies that have provided charitable support to CAC2 in our 2019 - 2020 fiscal year. CAC2's all-volunteer leadership team and diverse members are the heart of the organization and the reasons for its continued existence and achievements. Supporters of CAC2 make a difference for the 46 children who are diagnosed every day with one 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 experience lifelong, chronic health-related issues.

2021 Annual Summit Sponsors

Children's Hospital of Philadelphia
Alex's Lemonade Stand Foundation*
Cure 4 the Kids Foundation*
KPMG
Momcology*
The Morgan Adams Foundation*
YmAbs Therapeutics*

Hope Portal Support

Andrew McDonough B+ Foundation*
KBI Biopharma*

2019 CAC2 CureFest Reception Sponsor

Blackbaud

*denotes CAC2 member

Bioethics Think Tank Project Support

Elaine Roberts Foundation*
Steven L. Pessagno*

Sustaining Supporters (\$500+)

Joe Baber* (birthday fundraiser)
Digital Science & Research Solutions
GlaxoSmithKline Foundation
It's All About Christmas
Jaime L. Howard
Deborah* and John Kochevar
Northwest Indiana Cancer Kids
Foundation (NICK Foundation)*
Steven L. Pessagno*
Carol and Fred Schober
Sun East Charitable Foundation



members.cac2.org/donate



admin@CAC2.org



CAC2 | P.O. Box 41913
Philadelphia, PA 19101

THANK YOU!

CAC2 extends its deepest gratitude to all of our generous supporters in 2019-2020



SUPPORT

CAC2 receives both financial and volunteer support from corporations, organizations, and individual contributors.



Support for General Operations

Friends of CAC2 (donations \$50 - \$500)

Fran Andrews
Christine Antis
Patty Barrett
Linda Bornyas
Vickie and Walter Buenger*
Margaret and Tim Chandler
Lisa Clark
Amy McAuliffe Cooper
Arindam Dhar, MD
Jane Finlay
Theodore V. Jr. and Joan C. Foote
Gene and Sandy Gerner
Mark Giles
Kay Goodwin
Rebecca and David Hancock
Sarabjit Hart
Casey Holcombe
Christina Jones
Hilary Katz
Beatrice Kerridge
Saubiya Kidwai
Kurtis Kim, MD
Gillian Kocher
Laurie Lenox
Karen Juhasz
Joseph LaBarge
Mette Løchen

Kevin P. and Leslie G. McGinnis
Carla Petri McMullan
Victor Miller
Lauren Monks
Elise Morgan*
Kirsten Nathanson
Cheryl Posavac*
Carole Pessagno
M. Bookman and Florence Peters
Ron Raby
Gail Schwartz
Judy Stewart
Kim Wisner
Terri Witlin
Ernie and Marilyn Wright

Corporations and Philanthropic Organizations

Abbvie Foundation
AmazonSmile Foundation
Bristol-Myers Squibb Foundation
Erin's Dream Lanyards
Team Berlin Chess Club
PayPal Giving Fund

Individuals

Varshaa Alexis
Chris Anstey
Julie Milad Attala

Anne-Marie Banoub
Chris Bradie
Nicole Buitrago
Arbella Cherkis
Bryana Cole
Trish Dormer
Noah Eisenman
Marylou Finch
Kathryn Gaudreau
Kristina and Paul Giannaris
Martha Gordon
Victoria Hannah
Whitney Harrington
Ingram Hiu
Andrew and Susan L. Isles
Miray Mikhail Louffy
Katherine Luquette
Raquel McDaniel
Natalie Kostelni McGrory
Robin Markowitz
Rhonda Meaux
Charles J. Pessagno Jr.
Anadeli Salinas
Julianne Shafik
Mariam Shaphek





Every child deserves the chance
to live a healthy life.

CHILDHOOD CANCER FACTS

These are some of the facts about childhood cancers in the United States. To see our complete Fact Library full of sharable information, please visit cac2.org



- Cancer is the number one cause of death by disease among children.¹
- The incidence of childhood cancer is on the increase, averaging 0.7% increase per year since 1975 resulting in an overall increase of 24% over the last 40 years.²
- 46 children per day, or 16,780 children per year are expected to be diagnosed in 2020 with cancer.³
- 1 in 285 children is diagnosed with cancer by age 20.⁴
- Childhood cancer is not one disease – there are more than 12 major types of pediatric cancers and over 100 subtypes.⁵
- Childhood cancer survivors are at a 15-fold increased risk of developing Congestive Heart Failure and are at 7-fold higher risk of premature death due to cardiac causes, when compared with the general population. There is a strong dose-dependent relation between anthracycline chemotherapy exposure and CHF risk, and the risk is higher among those exposed to chest radiation.⁶
- Childhood cancer threatens every aspect of the family's life and the possibility of a future, which is why optimal cancer treatment must include psychosocial care.⁷
- Symptoms of post traumatic stress disorder are well documented for parents whose children have completed cancer treatment.⁸
- There are 70 potential life years lost on average when a child dies of cancer compared to 15 potential life years lost for adults.⁹
- One in four families lose more than 40% of their annual household income as a result of childhood cancer treatment-related work disruption.¹⁰
- More than 95% of childhood cancer survivors will have a significant health related issue by the time they are 45 years of age; these health issues are side-effects of the cancer or most commonly, its treatment. ⅓ will suffer severe and chronic side effects; ⅓ will suffer moderate to severe health problems; and ⅓ will suffer slight to moderate side effects.¹¹
- Since 1980, only four drugs have been approved in the first instance for use in children. Fewer than eight total drugs, also approved for use in adults, have been developed for use in children with cancer – compared with hundreds of drugs that have been developed specifically for adults only.¹²
- Childhood cancer survivors reported higher rates of pain, fatigue, and sleep difficulties compared with siblings and peers, all of which are associated with poorer quality of life.¹³
- Between 2009 and 2019, nine of the 11 drugs used to treat acute lymphoblastic leukemia, the most common childhood cancer, were in and out of shortage.¹⁴

1. National Vital Statistics Report, vol. 62.6, December 20, 2013, <http://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet>

2. National Institutes of Health Annual Report 2020, <https://www.nih.gov/news-events/news-releases/annual-report-nation-cancer-death-rates-continue-decline-2020>

3. American Cancer Society, A Journal for Clinicians, Cancer Statistics 2020, Table 12, <https://acsjournals.onlinelibrary.wiley.com/doi/full/10.3322/caac.21590>

4. American Society of Clinical Oncology (ASCO), <https://www.cancer.net/cancer-types/childhood-cancer/introduction>

5. American Cancer Society, Childhood and Adolescent Cancer Statistics, 2014

6. Lancet Oncology. 2015 Mar; 16(3): e123–e136. doi: 10.1016/S1470-2045(14)70409-7 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4485458/>

7. Institute of Medicine, 2008 – Cancer Care for the Whole Patient

8. Kazak et al., 2004 (Journal of Pediatric Psychology, 29 (3), p. 211-219)

9. National Cancer Institute, SEER Cancer Statistics Review 1973-1997 (NCI 2000) <http://inci.oxfordjournals.org/content/93/5/341.full>

10. The National Children's Cancer Society, The Economic Impact of Childhood Cancer, November 30, 2018 <https://www.thencs.org/wp-content/uploads/2017/04/the-economic-impact-of-childhood-cancer.pdf>

11. St. Jude Children's Research Hospital, (JAMA. 2013;309 [22]: 2371-2381)

12. National Cancer Institute, <http://www.cancer.gov/research/areas/childhood> https://www.cancer.gov/research/areas/childhood/fda-approved-drugs-childhood-cancers?cid=eb_govdel

13. Children's Oncology Group Long Term Follow-Up Guidelines, 2013

14. FDA Report Drug shortages <https://www.fda.gov/drugs/drug-shortages/report-drug-shortages-root-causes-and-potential-solutions>



MEMBERSHIP

CHILDHOOD CANCER ORGANIZATION MEMBERS

- Aiden’s Army

Eustis, FL

Alex’s Lemonade Stand Foundation

Bala Cynwyd, PA

Along Comes Hope

San Luis Obispo, CA

Amanda Hope Rainbow Angels

Phoenix, AZ

Andrew McDonough B+ Foundation

Wilmington, DE

aPODD Foundation

London, England, UK

Arms Wide Open Childhood Cancer Foundation

Marlboro, NJ

ASK Childhood Cancer Foundation

Richmond, VA

Beat Childhood Cancer Foundation

Tampa, FL

Bear Necessities Pediatric Cancer Foundation

Chicago, IL

Books That Heal

Kearny, NJ

Braden’s Hope for Childhood Cancer

Olathe, KS

Brooke’s Blossoming Hope for Childhood Cancer Foundation

Corpus Christi, TX

Caleb’s Crusade Against Childhood Cancer

Ft. Myers, FL

Cancer Families United

Kalamazoo, MI

CancerFree Kids

Loveland, OH

Candlelighters Childhood Cancer Foundation of the DC Metro Area

Merrifield, VA

Candlelighters of New York City

New York, NY

Canines-N-Kids Foundation

South Riding, VA

Carson Leslie Foundation

Dallas, TX

ccTHRIVE

Shelburne, VT

Childhood Cancer Awareness Group of Coffee County

Douglas, GA

Children’s Cancer Cause

Washington, DC

Children’s Cancer Research Fund

Minneapolis, MN

Christina Renna Foundation

Lindenhurst, NY
- CURE Childhood Cancer

Atlanta, GA

Cure 4 the Kids Foundation

Las Vegas, NV

Cure4Cam Childhood Cancer Foundation

Lyndell, PA

CureSearch for Children’s Cancer

Bethesda, MD

Dragon Master Foundation

Kechi, KS

Elaine Roberts Foundation

Alabaster, AL

Emily Whitehead Foundation

Philipsburg, PA

End Kids Cancer

San Luis Obispo, CA

Evan’s Victory Against Neuroblastoma Foundation

Germantown, MD

Fabulous Faith’s Foundation

Grand Prairie, TX

For A Day Foundation

Brooklyn, NY

Friends of Cathryn Foundation

Laguna Beach, CA

Gabriella’s Smile Foundation

San Antonio, TX

Gold in September Charitable Trust

Delafield, WI

Gold Rush Cure Foundation

Laguna Niguel, CA

Hugs for Brady Foundation

Kendall Park, NJ

I Care I Cure Childhood Cancer Foundation

Davie, FL

Jack’s Angels Foundation

Santa Clarita, CA

Jeff Gordon Children’s Foundation

Charlotte, NC

Jeremy Cares

Avon Lake, OH

Jessie Rees Foundation: Never Ever Give Up!

Irvine, CA

Joedance Film Festival

Charlotte, NC

Joey’s Journey Foundation

Noblesville, IN

Joey’s Wings Foundation

San Diego, CA

Journey4ACure

Broadlands, VA

Julia’s Grace Foundation

Royersford, PA

Kellen’s Krusade

Jackson, MI

- Kier’s Kidz

Highland Park, NJ

Ladybug House

Seattle, WA

Lighthouse Family Retreat

Atlanta, GA

Little Eric’s Foundation

Pittston, PA

Live Like Lukas

Wilmington, DE

Lolo’s Angels Inc.

Omaha, NE

Make Some Noise: Cure Kids Cancer Foundation

Morristown, NJ

Mattie Miracle Cancer Foundation

Arlington, VA

Max Cure Foundation

Englewood Cliffs, NJ

MIB (Make It Better) Agents

Barnard, VT

Momcology

Saint Johns, FL

Mystic Force Foundation

North Miami Beach, FL

Neuroblastoma Children’s Cancer Society

Hoffman Estates, IL

Northwest Indiana Cancer Kids Foundation

Schererville, IN

Open Hands Overflowing Hearts

Birmingham, AL

Pediatric Brain Tumor Foundation

Asheville, NC

Pediatric Cancer Foundation

Mamaronek, NH

People Against Childhood Cancer

Wilmington, NC

Precious Jules Childhood Cancer Foundation

Old Bridge, NJ

Richi Childhood Cancer Foundation

Brookline, MA

Ryan’s Case for Smiles

Wayne, PA

Sam Day Foundation

Portland, OR

Sammy’s Superheroes

Columbus, NE

SebastianStrong Foundation

Miami Springs, FL

Solving Kids’ Cancer

New York, NY

Sophia’s Fund

Marlborough, MA

Stand Firm Warrior Foundation

Denver, NC

- Steven G AYA Cancer Research Fund

Avon Lake, OH

Sweet Tea Cancer Connections

Renton, WA

Swiftly Foundation

Woodridge, IL

TeamConnor Childhood Cancer Foundation

Dallas, TX

Tennessee Cancer Consortium - Childhood Committee

Nashville, TN

The Catherine Elizabeth Blair Foundation

Washington, D.C.

The Grayson Saves Foundation

Hockessin, DE

The Lilabeen Foundation For Pediatric Cancer Research

Silver Spring, MD

The Morgan Adams Foundation

Denver, CO

The Ross K. MacNeill Foundation

Chicago, IL

The Taylor Matthews Foundation

New York, NY

This Star Won’t Go Out

Quincy, MA

Turn It Gold

Houston, TX

Tyler Robinson Foundation

Las Vegas, NV

Ty Louis Campbell Foundation

Carmel, NY

With Love Charity, Inc.

Jacksonville, FL

With Purpose

Charleston, SC

Zoe4Life

Gland, Switzerland

Zoefia Alexandria Foundation

Massapequa Park, NY

3/32 Foundation

Boonville, NC

STUDENT MEMBERS

- Alina Anderson

Omaha, NE

Bronson Balzac

Dallas, TX

Matt Buff

Saint Johns, FL

Maddie Curtis

Oak Hill, VA

Linnie Davis

Douglas, GA

- Olivia Grischow

Galena, OH

Bagisha Maitra

Bryan, TX

Anthony Moussa

Hilliard, OH

Wyatt Rech

Akeley, MN

Pallas Riedler

Rochester, NY

Polona Safaric Tepes

Cold Spring Harbor, NY

Hannah Staats

Marysville, OH

Riley Stock

Burleson, TX

Melodie Tedross

Houston, TX

Timmy Tran

Spencerport, NY

INDIVIDUAL MEMBERS

- Melissa Alderfer

Media, PA

Greg Aune

San Antonio, TX

Joe Baber

Virginia Beach, VA

Amelia Baffa

Wickliffe, OH

Carolyn Breinich

Sioux Falls, SD

Vickie Buenger

Bryan, TX

William Burns

Lavallette, NJ

Kimberly Chiulli

Troy, OH

Lisa Cleaton

New Bern, NC

Megan Coburn

Rockbridge, OH

Wendy Carvotta

Marietta, GA

Mary Beth Collins

Bel Air, MD

Casey Crossan

Oak Ridge, NC

Stephen Crowley

Washington, DC

Shane Dilling

Douglas, GA

Joseph Dudash, Jr.

Asbury Park, NJ

- Erin Ewald

Indianapolis, IN

Thad Ewald

Indianapolis, IN

Karla Flook

Fort Collins, CO

Judy Fulmer

Marion, SC

Amanda Griffin

Aldinga Beach, Australia

Bob Histing

Mobile, AL

Kevin J. Kane

Philadelphia, PA

Warren Kibbe

Chapel Hill, NC

Deborah Kochevar

Grafton, MA

TJ Koerner

Atlanta, GA

Mateusz Koptyra

Philadelphia, PA

Angela Lee

Schertz, TX

Maureen T. Lilly

Takoma Park, MD

Camille Loccisano

Brooklyn, NY

Jessica Lorenz

Brooklyn, NY

Robert Michael Madonna

West Chester, PA

D. Lee Marchiano

Nipomo, CA

Sarach McWhorter

Brownsburg, IN

Jen Merritt

Columbus, OH

Elise Morgan

Southampton, NJ

Laurie Orloski

Douglassville, PA

Steven L. Pessagno

Philadelphia, PA

Joan Pilko

Berwyn, PA

Tom Pilko

Berwyn, PA

Barbara Polo

Staten Island, NY

Cheryl Posavac

Philadelphia, PA

Ann Ramer

Brecksville, OH

Brian Riggs

Mickleton, NJ

- Stan Robbins

Columbus, OH

Neal Rourke

Desboro, ONT, Canada

Carleen Rufo-Miller

Rydal, PA

Nicoletta Sacchi

North Potomac, MD

Sheri Sallee

Omaha, NE

Tim Schmelz

International Falls, MN

Nadine Shapera

Denver, CO

Kelley Sharp

Raleigh, NC

Raquel Sticheran

College Station, TX

Micah Skeens

Columbus, OH

Jeffrey Skolnik

Malvern, PA

Barbara Solit

New York, NY

Susannah Koontz Webb

Houston, TX

SUPPORTING ORGANIZATIONS

- AstraZeneca

Gaithersburg, MD

Animal Cancer Foundation

Norwalk, CT

Association of Pediatric Hematology/Oncology Nurses

Chicago, IL

Bristol-Myers Squibb

Lawrenceville, NJ

GlaxoSmithKline

Collegeville, PA

KBI Biopharma

Durham, NC

Leukemia & Lymphoma Society

Rye Brook, NY

Loxo Oncology at Lilly

Stamford, CT

Making Cancer Fun

Franklin Lakes, NJ

National Brain Tumor Society

Newton, MA

Novartis Oncology

East Hanover, NJ

Y-mAbs Therapeutics

New York, NY



JOIN US

Help us advance the cause
for childhood cancer.

Visit: members.cac2.org



MEMBERSHIP BENEFITS

Join CAC2 and take advantage of the opportunities to establish strong relationships and to participate in coordinated action and collaborations with other groups and individuals that advocate for children and adolescents with cancer, survivors, and their families. Members also experience:

- Increased information sharing
- Optimal environment for collaborative initiatives
- Multiple opportunities to work with like-minded people
- Access to information & resources for patient and family support
- Enhanced integration of national and grass-roots advocacy efforts
- Discounted registrations at special programs
- Participation in the CAC2 Project Incubator

MEMBERSHIP CATEGORIES

Childhood Cancer Organizations

For organizations whose primary mission focuses on childhood cancer and related issues.

Individuals

For those (advocates, parents, survivors, healthcare professionals, scientists, etc.) not currently serving on the board or staff of either a childhood cancer organization or a supporting organization.

Supporting Organizations (non-voting members)

For organizations that do not focus exclusively on childhood cancer but who wish to support CAC2's mission.

Student Members (non-voting members)

For individuals who are currently enrolled in a school, college, or university.

IMPACT

Our 2019-20 initiatives and projects reflect our members' shared goals and values put into action and carried out under the stressful circumstances of a global pandemic and major economic disruption. Despite the challenge, we have worked to build sustainable, transparent, and credible unity among our members and provided them with opportunities to work together. We have placed our members at the center of our work and provided ample opportunities to learn, share information, and build bridges throughout the community.

We had an incredibly active and impactful year in advocacy and awareness. We pushed for and won substantial appropriations for the Childhood Cancer Data Initiative, the STAR Act, the Gabriella Miller Kids First Research Act, and pediatric initiatives with the Cancer Moonshot. Our research group made meaningful progress on a pair of member-led projects that hold much promise. We continued to improve and expand the Hope Portal, so that our family support group can help our members reach families regardless of where they are in their cancer journeys.

The work we do together resonates within CAC2 and across the community. We devoted substantial effort this year to engage our members as full and active partners and to expand both the ways we serve them and the opportunities we provide for them to work together on member-led initiatives. We continue to strengthen our structural foundation by adding new members, enhancing our technical capabilities, and improving the ways we communicate with each other, our partners, and the wider world. We work to be more impactful representatives of the community and lift up the spirit of collaboration and shared action as often as we can.

Work with us to create a world without childhood cancers and to support children and adolescents with cancer, their families, and those who survive their disease.



info@CAC2.org



members.cac2.org



CAC2 | P.O. Box 41913
Philadelphia, PA 19101





ACCELERATE Strategy Forum on Epigenetic Modifiers

CAC2 Members Brenna Carswell (Alex's Lemonade Stand Foundation), Joe McDonough (Andrew McDonough B+ Foundation), Susan Weiner (Children's Cancer Cause), Donna Ludwinski (Solving Kids' Cancer), and Vickie Buenger participated as patient advocates in the ACCELERATE Strategy Forum on Epigenetic Modifiers.



NCI Childhood Cancer Data Initiative Symposium

Several CAC2 members joined 500 other representatives from academic research institutions, government, industry, childhood cancer foundations, and advocates who convened to re-envision a national childhood data eco-system, a resource through which data sharing will enable the advancement of childhood cancer research and care.



CureFest: Community Engagement

CAC2 continues to be an active participant at CureFest held in Washington, DC each September. Our involvement includes promotion, hosting the annual CAC2 Welcome Reception, and manning a tent on the Mall. Thanks to Blackbaud and our members for making the Welcome Reception a great success!



Coordinated Action: Endorsing Standards of Care

CAC2 member organization Momcology endorsed fellow member the Mattie Miracle Foundation's tremendous project: the Psychosocial Standards of Care and committed to future collaboration with the Mattie Miracle Foundation to educate families on their rights as defined in the standards of care.



Pooled Funding: Low-Grade Glioma Study

CAC2 member organizations The Taylor Matthews Foundation and the Pediatric Brain Tumor Foundation pooled funds to jointly support a research study for pediatric low grade gliomas- affording eight children the opportunity to enroll in the study.



Pooled Funding: Drug Development

CAC2 members aPODD, Richi Foundation, B+ Foundation, and Jonathan Agin worked together to made a strategic early stage investment in Oncoheroes, crucial to prepare the company for its clinical development activities.



Coordinated Action: Vincristine Shortage Impact Survey

CAC2 members Momcology, Turn it Gold, Alex's Lemonade Stand, and Dr. Greg Aune joined forces to develop a Community Impact Survey as a call to action on the VNC shortage. The responses allowed regulators, physicians, policy makers, and advocates to gain a better understanding of the impact of the shortage within our community.



COLLABORATIVE HIGHLIGHTS

June 2019 - June 2020



Coordinated Action: Support & Awareness

CAC2 member organizations, Momcology and Children's Cancer Research Foundation co-sponsored four retreats and 25 coffee breaks for caregivers and worked together on four separate community awareness blog posts.



Coordinated Action: Family Assistance

CAC2 member organizations Sophia's Fund, Arms Wide Open Childhood Cancer Foundation, and Max Cure Foundation joined together to help a grieving single-mother following the death of her son who battled Choroid Plexus Carcinoma for six years.



Coordinated Action: Moonshot4Kids

CAC2 member organizations Jack's Angels, Dragon Master, Max Cure, Children's Cancer Cause, and National Brain Tumor Society participated in developing the DIPG Awareness Resolution and helped to organize a Congressional briefing to raise awareness of this cancer and highlight its high mortality rate.



Coordinated Action: Mutual Promotion

CAC2 members Greg Aune, Max Cure, and Solving Kids Cancer helped to bring answers to a community in turmoil over the COVID-19 crisis by co-promoting each others' webinars to get information into more people's hands.



Coordinated Action: #WhatCanIDo for COVID-19

CAC2 member organizations Be Strong, Fight On!, B+ Foundation, Leukemia & Lymphoma Society, and Momcology joined forces to create a coordinated action initiative infographic to share during the pandemic.



- Appropriations for Childhood Cancer Legislation
- September Landmark and Building Illumination Map
- September Awareness Resolutions
- International Childhood Cancer Awareness Day



ADVOCACY & AWARENESS

- Global Virtual Cancer Conference
- Hope Portal Updates & Outreach
- Survivorship Working Group & Blog



FAMILY SUPPORT & SURVIVORSHIP

- Bioethics Think Tank Project
- International Cancer Research Partnership
- ACCELERATE Strategy Forum
- Funding Match Project



RESEARCH & TREATMENT

- CAC2 Annual Summit
- Webinar Series
- Childhood Cancer Fact Library, 2019



EDUCATION

- CureFest
- Welcome Reception
- Public Webinar Vincristine Drug Shortage



COMMUNITY

- Leadership Succession Planning
- Erin's Dream Lanyards
- Website Refresh
- Development Collateral



SUSTAINABILITY



Putting children and families first
in everything we do.



- Books by Members
- Blogs by Members
- Visual Membership Directory



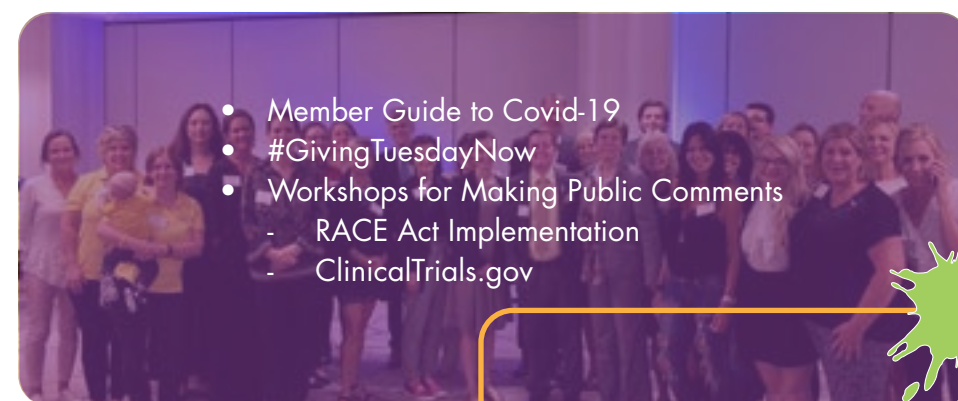
SPOTLIGHTING



- AACR-Sponsored FDA Listening Session on COVID-19
- ICRP COVID-19 Survey
- Momcology Vincristine Experience Survey



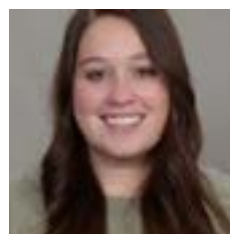
LISTENING



- Member Guide to Covid-19
- #GivingTuesdayNow
- Workshops for Making Public Comments
 - RACE Act Implementation
 - ClinicalTrials.gov



SUPPORTING



FundingMatch.com: CAC2's Searchable Website to Match Like-Minded Organizations

September 10, 2019: Melisse Skelton (CureSearch) and Oscar Ortiz (SebastianStrong) explained the latest project that is developing in the CAC2 Project Incubator, a searchable website to match like-minded organizations.



Collaboration and Progress: How Target Pediatric AML Facilitated LLS PedAL

October 2, 2019: TpAML co-founder/advocate Julie Guillot and Dr. Gwen Nichols, Chief Medical Officer, Leukemia & Lymphoma Society, highlighted the energy and work behind putting – and keeping – the patient at the center of drug development.



Special Community Webinar: Vincristine Drug Shortage Update

October 23, 2019: Dr. Adamson shared information the COG has received along with a perspective on childhood cancer drug shortages, including the current situation with vincristine.



Accelerating Drug Development for Children & Adolescents with Cancer

December 10, 2019: Dr. Gilles Vassal, chair of ACCELERATE, an international nonprofit, discussed ACCELERATE and its fresh approach to addressing the complex challenges of developing innovative pediatric cancer therapies in the new regulatory environment.



Tissue Donation: The Critical yet Overlooked Piece of the Research Puzzle

February 19, 2020: Dr. Reynolds and Dr. Waanders spoke on pre- and post-mortem tissue collection and explained how the availability of different types of tissue may hold the key to unlock the mysteries of childhood and AYA cancers.

As an educational service, CAC2 provides members with access to the latest information from top research scientists and thought leaders from across the country and around the world, through our webinar series.

Visit our Webinar Library at cac2.org/category/webinar/ to view a selection of past webinars.



Spring All-Member Webinar

March 18, 2020: CAC2 Board Members presented on our organization's recently updated strategic plan and a variety of other CAC2-related topics to give our members a solid understanding of what we are doing, why we are doing it, and how we can improve the ways we work together.



Cancer in Children with Birth Defects: Learn from Population-Based Studies

April 29, 2020: Drs. Jeremy Schraw and Philip Lupo of Baylor College of Medicine spoke about their research on nonchromosomal cancer predisposition.



What is a Pediatric Study Plan?

May 27, 2020: Dr. Brenda Weigel from University of Minnesota's Masonic Cancer Center and Dr. Samuel Blackman of Day One Biopharmaceuticals addressed: What is a Pediatric Study Plan (PSP)? How is it created and by who? How does FDARA/RACE for Children impact PSP development? Where in the process are the opportunities to create better PSPs?



The Art and Science of Navigating the Clinical Trials Landscape for Childhood Cancer

June 18, 2020: Brenna Carswell, Clinical Trials Navigator at Alex's Lemonade Stand Foundation, and Michael Wenger, Vice President of Patient Engagement at Trialscope, covered the basic trends, challenges, and solutions to improving access to clinical trials.



2019 SUMMIT

Nationwide Children's Hospital



6th Annual Summit

Members and guests gathered on June 21 and 22, 2019 at Nationwide Children's Hospital in Columbus, OH for the CAC2 6th Annual Summit and Members' Meeting. The two-day meeting featured rich programming, an abundance of networking opportunities, and action-oriented breakout sessions. The annual opportunity for our community to connect and share continues to open new doors for collaboration.

Our program included presentations on new immunologic therapies for childhood cancer, non-trial access to investigational drugs, biobanking in the context of cancer clinical trial, data sharing and Gabriella Miller Kids First Act, psychosocial impact of pediatric cancer on families, and panel discussions on survivorship and the progress and hurdles to better frontline treatment options. Investigators, clinicians, nurses, industry sponsors, and regulators joined members as we put a spotlight on the many ways we can work together to speed progress in the community.

The 2019 Summit featured our first "World Café" networking group dialogue activity, which provided attendees an exploratory method of rotating small-group conversations to finesse thought in search of progress and common ideas. This was an energized and highly effective way to reveal and explore the ideas and topics that our members care about and want to work on together in the following fiscal year. This format was highly effective in giving voice to our members around the issues that matter most to them. The outcomes from the World Café became the primary input to our Interest Group Breaks Out sessions (Advocacy & Awareness, Family Support & Survivorship, and Research & Treatment), which followed.

We extend our deepest gratitude to all the attendees, presenters, and sponsors for their support and participation. We would also like to acknowledge the outstanding efforts of the CAC2 Meeting Team, Program Team, Interest Group Leads, World Café organizers, and all the volunteers who worked tirelessly to ensure the success of the 2019 Annual Summit.



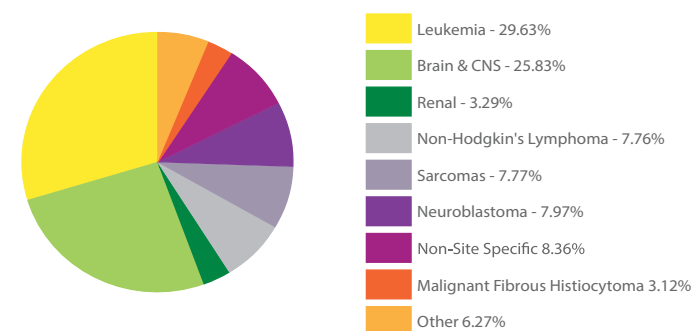
CAC2 joined the International Cancer Research Partnership (ICRPartnership.org), in 2015, after seeking the best opportunity for coordinated action, information exchange, education, and broad-based collaboration as related to research funding. The ICRP is a global alliance of cancer research organizations, and its database houses more than 105,000 grant records for cancer research. This partnership provides CAC2 members full access to view funded projects, as well as information on researchers from around the world. This database currently hosts information on 853 childhood cancer research projects funded by CAC2 members, and 5,276 childhood cancer projects in total. Together we are making the database more robust and creating a more accurate view of the childhood cancer research landscape.

Collaborating to provide funding data in a central repository of pediatric cancer research studies is an effective means to assess funding priorities and gaps. In addition, it has helped to raise awareness in the cancer community about relevant funding projects and potential for partnerships. CAC2's contribution to the ICRP has helped the ICRP database raise the profile of childhood cancer and create a more complete picture of global funding for childhood and AYA cancers.

Research Investment Breakdown by CSO Category



Research Investment Percentages by Cancer Type



When CAC2 joined the ICRP in 2015, the ICRP subsequently applied a retroactive and unique code for childhood cancers allowing for a novel ability to search specifically for childhood cancer projects among the approximately 80,000 data entry sets. Additionally, since CAC2 joined the ICRP, the number of childhood cancer projects listed in the ICRP portfolio has more than doubled, due in large part to the addition of CAC2 member funding projects submitted.

Our participation in the ICRP has also led to a greater understanding of the science CAC2 member organizations fund as a whole, and allows members to see their collective data in a new way. The platform allows our members to evaluate and assess funding strategies based on examination of not only their own funding, but also the data supplied by other childhood and AYA cancer and survivorship funders.

There are currently 100 organizations around the world reporting a cumulative 5,276 childhood cancer funding projects. These represent an average of \$231M in annual, wholly-focused childhood cancer projects funded by submitting organizations.

Your Gateway to Support Resources

For childhood cancer patients, survivors, and their families



- Psychosocial
- Camps
- Siblings
- Teens
- Bereavement
- Survivorship
- Info & Tips
- Scholarships
- Transportation
- Expenses & Medical Bills
- Wishes & Gifts
- In-Person Support

Visit the Hope Portal, where finding support for childhood cancer families is just a click away.



CAC2.org ■ info@cac2.org

Coalition Against Childhood Cancer ■ PO Box 41913 ■ Philadelphia, PA 19101

