



2020-2021 ANNUAL REPORT



CAC2
Coalition Against Childhood Cancer

CAC2.org



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.

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PRESIDENT'S MESSAGE

Members and Friends,

I'd like to welcome our new members. In the last year we have added 11 new Member Organizations, 16 new Individual Members, 2 new Student Members, and 3 new Supporting Organizations to our membership. I'd also like to thank our faithful renewing members! Together we have accomplished much.

Rather than summarize the contents of this report, I'd like to take this space to express my enormous gratitude to CAC2's members and supporters who have made my time as President so fulfilling and productive. My husband often referred to my volunteer role as President of CAC2 as "my wife's robust non-paid work," but I always thought of it as the perfect complement to my professional and personal life.

At my first Annual Summit as CAC2's President, Joy Cruse (TeamConnor Foundation) introduced me by comparing me to a viticoltore she had met at a vineyard in Italy. She described how, like this woman who tenderly tended her family's grapevines, Vickie Buenger loved each and every one of her "grapes." I'm not sure how Joy had seen into my heart, but it is true: I love each and every one of our members. I cherish the experiences I've had learning from and guiding CAC2 over the past eight years and salute everyone within CAC2 who has touched and enriched my life.

My planned obsolescence with built-in term limits and a well-executed leadership transition plan makes my next chapter within CAC2 a perfect fit. Managing Director Mandy Spielvogle Powell has already demonstrated her deft touch with communications and amazing aptitude for overseeing the day-to-day administration of our organization. New Board Chair Amy Weinstein (Pediatric Brain Tumor Foundation) has prepared for this inaugural CAC2 role over the past year, and her leadership has shined brilliantly in the transition. As President Emeritus, I will continue to volunteer with energy and imagination, focusing my attention on a portfolio of activities that includes maintaining our external relationships, enhancing learning and educational opportunities, and helping out where my skills and experiences can make the most impact.

Ending my final year as President is not the same as riding off into the sunset. Children and teens with cancer, their families, and the wider community of survivors need all of us to do our parts, and we are stronger when we stick together. Thank you for your trust and partnership and the opportunity to serve.

With everlasting appreciation,

Vickie

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 four basic pillars of interest that our members share: Awareness & Advocacy Support, Research & Treatment, Family Support, and 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.

While our members fund research and support families differently, CAC2 does not. Instead, CAC2 focuses on activities that cannot be effectively and efficiently delivered in the absence of coordinated action. 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.

In April, CAC2 welcomed Mandy Spielvogle Powell as our first Managing Director. Mandy brings to CAC2 more than 15 years of leadership experience in non-profit organizations and educational institutions. Our new Managing Director position was created to manage the day-to-day operations of CAC2 and facilitate communication across the organization. In addition, our Managing Director will work to enhance the structures and processes that guide and support our collaborative work.

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 with children with cancer. They may have survived childhood cancer themselves. Or they may just feel a close personal connection to the cause.

What unites all of us 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.



Meet Mandy!



MISSION

The Coalition Against Childhood Cancer, 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 Support, Survivorship, and Research & Treatment.

VISION

CAC2 serves all stakeholders in the pediatric cancer space and strives to unite and amplify the collective efforts of the childhood cancer community. CAC2 exists to ensure that the childhood cancer community benefits from greater levels of coordinated action and collaboration that leverage the unique strengths of its members, minimize waste of precious resources and expertise, and drive better outcomes for patients and their families. We envision a world without childhood cancers.



VALUE STATEMENT

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.



LEADERSHIP

Vickie Buenger, President
Independent Advocate

Sarah Bartosz, Leadership Transition Team
Beat Childhood Cancer and Gold In September (G9)

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

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

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

Kim Buff, Membership Lead
Momcology

Amy Godkin, Family Support Liaison
ASK Foundation

Jeremy Bilier, Technology Lead
Gold Rush Cure

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

Ginny McLean, Awareness Liaison
Swiftly Foundation

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

Tom Pilko, Nominating Chair
Independent Advocate

Amy Weinstein, Vice President & Research Liaison
Pediatric Brain Tumor Foundation



TREASURER'S REPORT

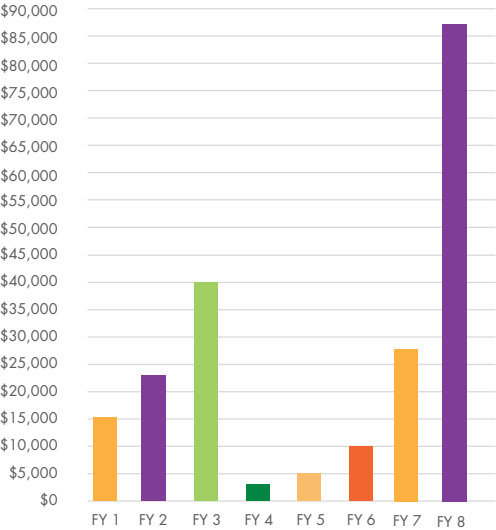
Midway through 2020, CAC2 – like all organizations – was adjusting its plans to the realities of the coronavirus pandemic as its 8th Fiscal Year (FY8) began on July 1, 2020. After holding a limited, virtual adaptation of its signature Annual Summit in July 2020, the Board of Directors focused on how CAC2 could support childhood cancer organizations through such a challenging time. These organizations were working hard to figure out how to pivot from their largest source of funding (in-person events) while continuing to further their missions to advocate, provide research funding, deliver family support or survivorship programs that serve pediatric and adolescent cancer patients, survivors, and their families. CAC2 focused our resources on ways to share information, tools, and best practices on how to weather the pandemic storm – which also led to new opportunities for collaboration among all of our members, as detailed in this Annual Report.

All the while, the Board of Directors planned for possible impacts to CAC2 itself. As membership revenue typically accounts for 60% of CAC2's revenue in any given fiscal year, this was – and remains – an important topic. We weren't sure what to expect, but we ultimately realized a net gain of 15 new members this year, starting FY8 with 180 members and ending it with 195 members. CAC2 and its members certainly demonstrated resilience throughout this past year, employing creative ways to transform their organizations and finding new ways to work collectively to accelerate their progress in the fight against childhood cancer.

In an unusual year, CAC2 is grateful to have benefited from an unexpected and very generous grant from Amazon in the amount of \$100,000. As CAC2 typically receives \$40,000-\$50,000 in support of its general operations and collaborative initiatives, the Amazon grant will be classified as an "unusual grant" on its Form 990 for FY8. We certainly hope and plan to receive larger grants such as the Amazon gift going forward so that they will become "usual" for CAC2 in the years to come – because our members have ambitious plans for the benefit of childhood cancer

patients, survivors, and their families. The Amazon grant enabled CAC2 to create a partnership with the American Childhood Cancer Organization (ACCO) to deliver a state cancer action plan training meeting for advocates in May as well as to further CAC2 advocacy-focused initiatives such as the Childhood Cancer State License Plate Map and our State Cancer Control Plans Working Group. Accordingly, CAC2 is planning to expand our collaborative infrastructure, and this will take funding and other support from new and existing philanthropic supporters alike.

CAC2 Net Income



CAC2 Revenue and Expense History




As always, we thank everyone who has believed in CAC2, supported our mission, and enabled our membership to achieve "8 for 8" 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.

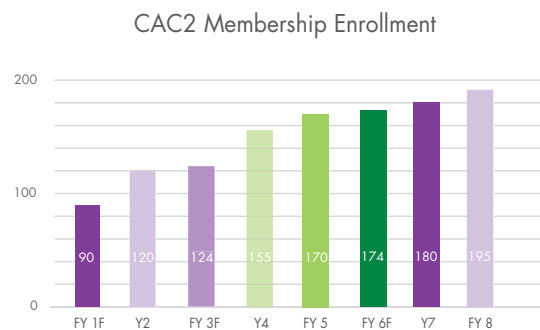
Steven L. Pessagno
 Steven L. Pessagno
 Treasurer, Coalition Against Childhood Cancer



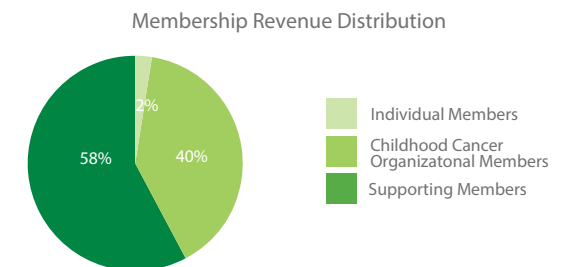
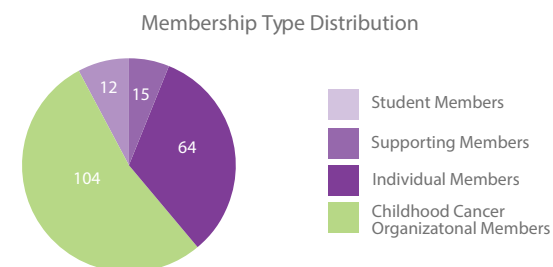
195 
Current Members

81% **Renewal Rate**


CAC2 is a membership organization that functions because of and for its members. 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.



Our members and 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.



40%

While Student, Individual, and Organizational Members combined 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.

58%

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.

Game changer

DONORS ROCK!

WOW!

AWESOME

FOR OUT

Respect

WOW!

"THANKS!!"

Thank You

GOLD

SUPPORTERS

CAC2 extends its deepest gratitude to each of our very generous supporters in 2020-2021

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

Individuals

Cary Armstrong
Fran Andrews
Christine Antis
Vickie* and Walter Buenger
Coleen Caleshu
Maggie and Tim Chandler
Kristina Conrad
Jonathan Coopersmith
Tracy Coyne
Hannah Cytron
Jillian Davies
Ginger Diamond*
Carmella and George C. Edwards
Whitney Ford
Kay Goodwin
Rebecca and David Hancock

Darlene Haven
Michelle Hearn
Gina Koebke
Kiley Johnson
Susan McKiernan
Nancy and Ted Paup
Amy Powers
Cherie Rao
Kaylene Ready
Taryn Rosenthal
Nicoletta Saatchi*
Diane B. and Dennis D. Schafer
Cheri Schoonveld
Anne Siebold
Ernie and Marilyn Wright
Monica Zarb

Corporations and Philanthropic Organizations

Abbvie Foundation
AmazonSmile Foundation
Bristol-Myers Squibb
PayPal Giving Fund
Pledgling Foundation
PWC Community Fund
The Secret Dark Night Society Chess Club of Columbus, OH
Vanguard Community Fund

*denotes CAC2 member

Special Grant for
Advocacy-Focused Initiatives
Amazon

Sustaining Supporters (\$500+)

C. Davis Buenger
Vickie Buenger* (birthday fundraiser)
GlaxoSmithKline Foundation*
Jaime L. Howard
JP Morgan Chase Foundation
Deborah* and John Kochevar
Northwest Indiana Cancer Kids Foundation (NICK Foundation)*
Steven L. Pessagno* (birthday fundraiser)
Sun East Charitable Foundation
Matt C. Taylor*

Hope Portal In-Kind Support
KBI Biopharma*

Annual Endowment for the Bob Piniewski
Volunteer of the Year Award
Andrew McDonough B+ Foundation*

2021 Annual Summit Sponsors

Alex's Lemonade Stand Foundation*
Cure 4 the Kids Foundation*
Day One Biopharmaceuticals*
KPMG Philadelphia
Momcology*
Northwestern Mutual Philadelphia
Oncoheroes Biosciences*
The Morgan Adams Foundation*
Y-mAbs Therapeutics*



cac2.org/donate



admin@CAC2.org



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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

47 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.⁵

On average, about 17% of children die within five years of diagnosis. Among those children that survive to five years from diagnosis, 18% will die within 30 years of diagnosis.

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. 1/3 will suffer severe and chronic side effects; 1/3 will suffer moderate to severe health problems; and 1/3 will suffer slight to moderate side effects.

Through 2020 the FDA has approved a total of 34 drugs for use in the treatment of childhood cancers. 28 of the drugs were originally approved only for adult use. Today we have only six drugs that were approved in the first instance for use in cancer treatment for children.³

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.

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 NIH/National Cancer Institute, Age-Adjusted and Age-Specific SEER Cancer Incidence Rates, 2014-2018, Table 2.1 https://seer.cancer.gov/csr/1975_2018/results_single/sect_02_table.01_2pgs.pdf Citation for drug: National Cancer Institute, http://www.cancer.gov/research/areas/childhood/fda-approved-drugs-childhood-cancers?cid=eb_govdel
 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, <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2014/special-section-cancer-in-children-and-adolescents-cancer-facts-and-figures-2014.pdf>
 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 Journal of the National Cancer Institute "Cause-Specific Late Mortality Among 5 Year Survivors" <http://jnci.oxfordjournals.org/content/100/19/1368.full>
 8 National Cancer Institute, SEER Cancer Statistics Review 1973-1997 (NCI 2000) <http://jnci.oxfordjournals.org/content/93/5/341.full>
 9 Journal of the National Cancer Institute "Cause-Specific Late Mortality Among 5 Year Survivors" <http://jnci.oxfordjournals.org/content/100/19/1368.full>
 10 Institute of Medicine, 2008 – Cancer Care for the Whole Patient
 11 Kazak et al., 2004 (Journal of Pediatric Psychology, 29 (3), p. 211-219)
 12 Kazak et al., 2004 (Journal of Pediatric Psychology, 29 (3), p. 211-219)
 13 Children's Oncology Group Long Term Follow-Up Guidelines, 2013





MEMBERSHIP

CHILDHOOD CANCER ORGANIZATION MEMBERS

Aiden's Army
Eustis, FL

Alex's Lemonade Stand Foundation
Wynnewood, 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

Bear Necessities Pediatric Cancer Foundation
Chicago, IL

Beat Childhood Cancer
Tampa, FL

Books That Heal
New York, NY

Braden's Hope for Childhood Cancer
Olathe, KS

Braver Stronger Smarter, Inc.
Mildura, Victoria, AU

Brooke's Blossoming Hope for Childhood Cancer Fund
Chapman Ranch, TX

Caleb's Crusade Against Childhood Cancer
Fort Myers, FL

Cancer Families United
Kalamazoo, MI

CancerFree Kids
Loveland, OH

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

Connect4Cancer
Encino, CA

Cure 4 the Kids Foundation
Las Vegas, NV

CURE Childhood Cancer, Inc.
Atlanta, GA

Cure4Cam Childhood Cancer Foundation
Lyndell, PA

CureSearch for Children's Cancer
Bethesda, MD

Daniela Conte Foundation
Dix Hills, NY

DC Candellighters
Centreville, VA

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
Pearl, MS

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

Hope for Steam Learning Inc.
Plainsboro, NJ

HOPE4ATRT Foundation
New York, NY

Hugs for Brady Foundation
Kendall Park, NJ

Jack's Angels
Santa Clarita, CA

Jeff Gordon Children's Foundation
Charlotte, NC

Jeremy Cares
Avon Lake, OH

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 Crusade
Jackson, MI

Kiers Kidz
Highland Park, NJ

Ladybug House
Seattle, WA

Lighthouse Family Retreat
Atlanta, GA

Little Eric's Foundation
West Pittston, PA

Live Like Lukas, Inc.
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 Agents Osteosarcoma Alliance
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, NY

People Against Childhood Cancer (PAC2)
Wilmington, NC

Precious Jules Childhood Cancer Foundation
Old Bridge, NJ

PREP4Gold
Reston, VA

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

Smashing Walnuts
Leesburg, VA

Solving Kids' Cancer
New York, NY

Sophia's Fund
Marlborough, MA

Spada Pediatric Sarcoma Foundation
Brookfield, WI

Stand Firm Warrior Foundation
Denver, NC

Steven G. Cancer Foundation
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 Memorial Foundation
Washington, D.C.

The Grayson Saves Foundation
Hockessin, DE

The Kortney Rose Foundation
Oceanport, NJ

The Lilabeau Foundation For Pediatric Cancer Research
Silver Spring, MD

The Morgan Adams Foundation
Denver, CO

The Oliver Foundation
Miami Beach, FL

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

Zoe4Life
Gland, Switzerland

Zoefia Alexandria Foundation
Massapequa Park, NY

3/32 Foundation
Boonville, NC

SUPPORTING ORGANIZATIONS

Animal Cancer Foundation
Port Washington, NY

Association of Pediatric Hematology/Oncology Nurses
Chicago, IL

AstraZeneca
Wilmington, DE

Bristol Myers Squibb
New York, NY

Day One Biopharmaceuticals
South San Francisco, CA

GlaxoSmithKline
Collegeville, PA

KBI Biopharma
Durham, NC

Leukemia & Lymphoma Society
Rye Brook, NY

LivingLFS
Kennewick, WA

Loxo Oncology at Lilly
Stamford, CT

Making Cancer Fun
Franklin Lakes, NJ

National Brain Tumor Society
Newton, MA

Novartis Oncology
East Hanover, NJ

Oncoheroes Biosciences Inc.
Brookline, MA

Y-mAbs Therapeutics
New York, NY



Membership (con't.)

INDIVIDUAL MEMBERS

Greg Aune
San Antonio, TX
Joe Baber
Virginia Beach, VA
Carolyn Breinich
Columbus, OH
Nigel Brockton
Arlington, VA
Vickie Buenger
Bryan, TX
William Burns
Lavallette, NJ
Cathy Carver
Las Cruces, NM
Wendy Carvotta
Woodstock, GA
Kimberly Chulli
Troy, OH
Lisa Cleaton
New Bern, NC
Megan Coburn
Rockbridge, OH
Casey Crossan
Oak Ridge, NC
Stephen Crowley
Washington, DC
George Dahlman
Richmond, VA
Shane Dilling
Douglas, GA
Joseph Dudash, Jr.
Asbury Park, NJ
Erin Ewald
Indianapolis, IN
Thaddeus Ewald
Indianapolis, IN
Karla Flook
Fort Collins, CO
Serena Gaines
Bennington, NE
Carrie Giest
Pittsburgh, PA
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
Susannah Koontz
Houston, TX

Mateusz Koptyra
Philadelphia, PA
Angela Lee
Schertz, TX
Mark Levine
Stoughton, MA
Maureen T. Lilly
Takoma Park, MD
Camille Loccisano
Brooklyn, NY
Jessica Lorenz
Brooklyn, NY
Robert Michael Madonna
West Chester, PA
D. Lee Marchiano
Guadalupe, CA
Tabitha McCollum
Cibolo, TX
Sarah McWhorter
Brownsburg, IN
Jen Merritt
Columbus, OH
Elise Morgan
Voorhees, NJ
Hannah Neff
Berkeley, CA
Danelle Nielson
Layton, UT
Laurie Orloski
Douglassville, PA
Cruz Perez-Jimenez
El Paso, TX
Steven L. Pessagno
Philadelphia, PA
Joan Pilko
Berwyn, PA
Tom Pilko
Berwyn, PA
Barbara Polo
Staten Island, NY
Cheryl Posavac
Philadelphia, PA
Juanita Prada
Roanoke, VA
Ann Ramer
Brecksville, OH
Brian Riggs
Mickleton, NJ
Stan Robbins
Columbus, OH
Ulonda Rogers
Bryan, TX
Neal Rourke
Desboro, ON, Canada
Carleen Rufo-Miller
Rydal, PA

Nicoletta Sacchi
North Potomac, MD
Sheri Sallee
Omaha, NE
Tim Schmelz
Springfield, MO
Nadine Shapera
Denver, CO
Kelley Sharp
Raleigh, NC
Raquel Sitcheran
College Station, TX
Jeffrey Skolnik
Cherry Hill, NJ
Barbara Solit
New York, NY
Matt Taylor
Houston, TX
Tara Waters
Weymouth, MA
Kelli Wright
Bethesda, MD

STUDENT MEMBERS

Alaina Anderson
Omaha, NE
Bronson Balzac
Dallas, TX
Matt Buff
Saint Johns, FL
Bagisha Maitra
Bryan, TX
Anthony Moussa
Hilliard, OH
Wyatt Rech
Akeley, MN
Hannah Staats
Marysville, OH
Riley Stock
Burleson, TX
Melodie Tedross
Houston, TX
Mirelle Tedross
Houston, TX
Timmy Tran
Spencerport, NY
Susan Willman
Palm Harbor, FL

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 missions is focused on childhood cancer and related issues.

Individuals

For those (advocates, parents, survivors, doctors, health-care 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.



info@CAC2.org



members.cac2.org



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



IMPACT

As always, our 2020-21 initiatives and projects reflect our members' shared goals and values. Despite the ongoing global pandemic and accompanying economic, social, and psychological struggles, CAC2 and its members have carried out an impressive array of activities, such as planning for and hiring our first Managing Director, Mandy Spielvogel Powell, completing our eighth collaborative project, launching a state cancer advocacy initiative, and implementing much-needed technology and database upgrades.

The work we do together resonates within CAC2 and across the community. Our impact flows from the activities we undertake and is amplified by the strength and reach of our members. Together, we represent the following:

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

To optimize our efforts, we engage our members as active partners and work every day to expand the ways we serve them and provide opportunities for them to work together on member-driven initiatives. As always, we work to create a world without childhood cancers and to support children and adolescents with cancer, their families, and those who survive their disease.



Celebrating the collaborative successes of our members and CAC2!



Coordinated Action: Support during COVID

CAC2 member organizations Solving Kids Cancer, Momcology, Ty Louis Campbell Foundation, and Max Cure Foundation worked collaboratively with Friends of Karen to host an expert-led community discussion for families about coping with the COVID-19 pandemic.



Funding Partnership: Neuroblastoma

CAC2 member organizations Solving Kids Cancer and Zoe4Life joined a larger partnership of childhood cancer organizations. Collectively, they gifted \$1.3M to fund a clinical trial at Children's Hospital of Philadelphia and Gustav Roussey for neuroblastoma that includes a targeted agent.



Funding Partnership: Ewings Sarcoma

CAC2 member organizations Spada Pediatric Sarcoma Foundation and Sam Day Foundation contributed a starting corpus of \$250,000 to a fund at CAC2 member organization Beat Childhood Cancer. The team created a Ewings specific fund at Beat Childhood Cancer to help drive genomic sequencing in tumors to investigate pathways and targets.



Funding Partnership: New Therapies

CAC2 members Andrew McDonough B+ Foundation, Children's Cancer Research Fund, and Jeff Gordon Children's Foundation have made meaningful contributions in Oncoheroes Biosciences, a CAC2 Supporting Member, to help accelerate the development of new therapy options for children and adolescents with cancer.



Collaboration about Collaboration

CAC2 members Vickie Buenger and Amy Weinstein (Pediatric Brain Tumor Foundation) presented a webinar for ICRP/NCRI highlighting how cancer research funders are currently collaborating to advance pediatric cancer research and clinical care.



ACCELERATE International Collaboration Working Group

CAC2 Members Nicole Scobie (Zoe4Life), Donna Ludwinski (Solving Kids' Cancer), and Vickie Buenger are members of this working group to identify real obstacles to international cooperation, to develop principles and best practices for global clinical research in the US-EU-UK-Canada-JAPAN to enable pediatric oncology focused cooperative groups and clinical trial centers to collaborate and to ACCELERATE drug development to provide synergy with other working groups and the ITCC Sponsor Committee.



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.



ACCELERATE Meeting on (ALK) Inhibition

CAC2 Members Joe McDonough (Andrew McDonough B+ Foundation), Susan Weiner (Children's Cancer Cause), Nicole Scobie (Zoe4Life), and Vickie Buenger along with three other advocates presented a robust call for action urging researchers to keep time in mind as a pressing consideration in the conduct of pre-clinical and clinical research for our children.

ADVOCACY



- Successful Legislative Pushes
- Creating Hope Act Reauthorization
 - \$30 million to implement the STAR Act
 - \$50 million for the Childhood Cancer Data Initiative
 - \$12.6 million for Gabriella Miller Kids First Act
- Advocacy Support
- Gabriella Miller Kids First Research Act 2.0
 - DIPG Resolution (H.Res. 404)
- Primer on State Cancer Action Plans Training Meeting
Sign-On Study Group

FAMILY SUPPORT



- Family Support Survey
Hope Portal
- 381 organizations and support for all 50 states
 - 34,982 visitors to the site last year
 - Spring Cleaning
 - State Liaison Initiative

RESEARCH & TREATMENT



- Bioethics Think Tank Project
Funding Match Project Beta Test
ICRP 20% growth in listed projects
ICRP Webinar "How Collaboration is Advancing Research and Clinical Care in Pediatric Cancer"

AWARENESS



- Unified September Awareness Campaign
Shining the Light Virtual Candle Campaign
Illuminations (including the White House!)
Shine a Light on the Longest Night Campaign
Fact Library Infographics Collection
Support of Community Campaigns
- National Cancer Prevention Month
 - World Cancer Awareness Day
 - International Childhood Cancer Awareness Day
 - Rare Disease Day
 - Li-Fraumeni Syndrome Awareness Day
 - AYA Cancer Awareness Week

SURVIVORSHIP



- Hope Portal Survivorship Resource Drive
Better Together Database
CAC2 Connection
- Better Together – Phase 2 submitted to the Project Incubator
 - "Hope Portal Survivorship Expansion" initiative
 - Survivorship Toolkit Planning

OPERATIONS & SUSTAINABILITY



- Successful Managing Director Hiring Process
Increased Number and Size of Financial Partnerships
Successful Data Migration to Salesforce and Stripe
Member Services
- Member Hub Debut
 - Virtual Membership Directory
 - Monthly Announcements
 - Member Spotighting
 - Navigating COVID guide

EDUCATION



- CAC2 Annual Summit
Webinar Series
Childhood Cancer Fact Library
Childhood Cancer Community News

FOSTERING COLLABORATION



- Co-Host and Promote Webinars & Meetings
Updated CAC2 Member Guide to Navigating the Covid-19 Crisis
Sign-On Opportunities
- GBM Awareness Day Resolution
 - Brain Tumor Patients' Charter of Rights
 - Make Childhood Cancer a National Priority
- Promotion and Support Provided
- Virtual CureFest
 - Rally for Medical Research
 - Virtual Action Days
 - ACCELERATE Pediatric Oncology Conference



WEBINARS



2020 SUMMIT



Improving Time to Diagnosis for Pediatric and Young Adult Cancer Patients

Sue Guisto (Friends of Cathryn Foundation) and Steve Crowley helped us host a speaker program that included Drs. David Walker and Scott Coven. The presenters founded the UK's Head Smart Program which has effectively addressed delayed diagnosis in children's brain tumors.

Liquid Biopsy for Early Detection in Patients with Cancer Predisposition Syndromes

In April's CAC2 All-Member Webinar, Dr. Brian D. Crompton (pediatric oncologist at Dana Farber/Boston Children's Hospital) and CAC2 Member Greg Harper (Living LFS) presented about the possibilities of emerging technology in identifying circulating cancer cells with liquid biopsies, using Li-Fraumeni Syndrome as a case study.

Childhood Cancer Advocacy: Action Day 2021

In April's Special Edition CAC2 All-Member Webinar CAC2 Member Danielle Leach (National Brain Tumor Society and the Alliance for Childhood Cancer) highlighted the opportunity for online issues and advocacy training through pre-arranged Zoom meetings with Members of Congress and their staffs.

20 Years of Neuroblastoma Research Progress

CAC2 Member Gavin Lindberg (EVAN Foundation) hosted a speaker program that included Drs. Kate Matthay, Judy Villablanca, and Steve DuBois speaking on 20 Years of Neuroblastoma Research Progress. These leaders of the New Approaches to Neuroblastoma Therapy (NANT) consortium informed the audience about the progress and challenges associated with developing new strategies for refractory and relapsed neuroblastoma patients. We also learned about the history of this 20 year-old, multi-institution network, their collaborations with partners, current clinical trials and plans for future studies.

Pediatric Cancer Data Commons: A Story of Impact and Promise

CAC2 Member Mariah Forster Olson (Neuroblastoma Cancer Research Foundation) introduced Dr. Sam Volchenbom, who spoke about his work leading the Pediatric Cancer Data Commons at the University of Chicago. During the presentation Volchenbom highlighted the ways in which data science is advancing pediatric cancer research and discussed how this work can be influential for cancer survivors.

An Ounce of Prevention, A Lifetime of Health: Childhood Cancer Prevention Initiative

Dr. Margaret Kripke, Professor of Immunology and Vivian L. Smith Chair Emerita at the University of Texas M.D. Anderson Cancer Center and Dr. Philip Landrigan, Professor of Biology at Boston College and Director of the Program for Global Public Health and the Common Good joined CAC2 Members Jonathan Agin (Max Cure Foundation), Mary Beth Collins, and Anne Robertson to discuss a soon-to-be unveiled childhood cancer prevention initiative. The panel discussion provided an overview about the history of environmental toxicities, what is currently taking place to command a discussion with key influencers, and what parents and advocates can do about this important issue.

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

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 in trial enrollment and the challenges and solutions to improving access to clinical trials for children and teens with cancer. Both Brenna and Michael are cancer survivors!

8th Annual Summit and Members' Business Meeting July 17, 2020

In the face of a pandemic, our agile Meetings Team designed a carefully curated two-hour version of our traditional Annual Summit. Embracing the virtual opportunity to gather in community, the Coalition Against Childhood Cancer was pleased to host more than 100 people for the 2020 CAC2 Annual Summit. Guests had the opportunity to learn from a splendid slate of speakers and engage in an important business meeting.

Dr. Doug Hawkins, the newly elected Chair of the Children's Oncology Group (COG) shared his vision for COG, and offered a Q&A with our summit attendees on how parent patient advocates fit into that vision. The Summit also featured a panel discussion of the RACE Act, that was moderated by Dr. Stacey Adam (FNIH), featuring Dr. Malcolm Smith (NCI), Dr. Martha Donoghue (FDA), and Dr. Mark Kieran (Bristol Myers Squibb), and included discussions of the possibilities for pediatric oncology drug development presented by regulations going into effect in August 2020.

2020 CAC2 Volunteers-of-the-Year



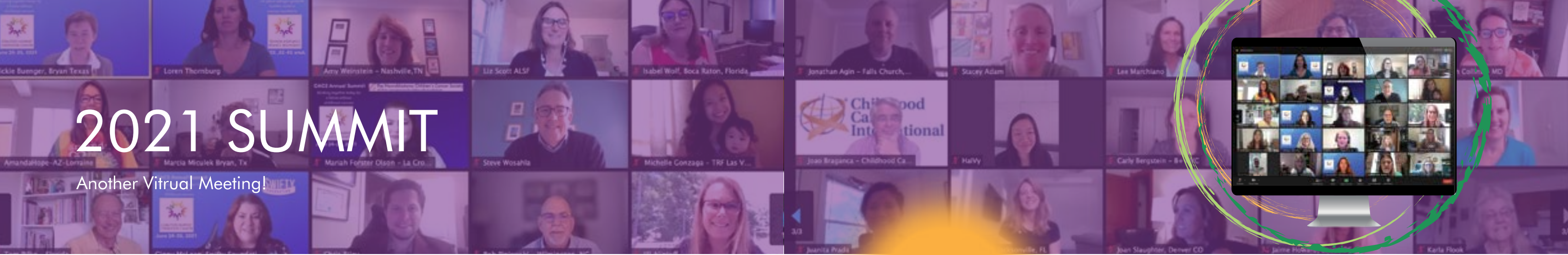
Robin French



Joanne Salcido

The CAC2 Board and Members extend a warm thank you to Joanne Salcido (Pediatric Brain Tumor Foundation) and Robin French (The Morgan Adams Foundation) for their outstanding commitment to excellence in content and logistics for the CAC2 Webinar Series, which has grown and improved under their dedicated stewardship.



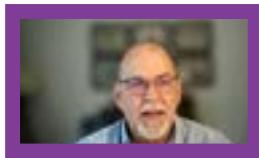


2021 SUMMIT

Another Virtual Meeting!

9th Annual Summit

Introducing the Bob Piniewski CAC2 Volunteer-of-the-Year Award



Bob Piniewski, PAC2 - Award Namesake

The Bob Piniewski Volunteer-of-the-Year Award, endowed by Joe McDonough of the Andrew McDonough B+ Foundation, goes to a CAC2 volunteer who, through their volunteer effort in the most recent year, best exemplifies the CAC2 Mission to put children and their families first in everything and support childhood cancer organizations active in the fight against cancer. Through Joe's generosity and in honor of Bob's desire that we take every opportunity to support each other, the award includes a prize of \$1,000 payable to the organization(s) chosen by the recipient.

The First Annual Bob Piniewski Volunteer-of-the-Year Award Recipient



Jeremy Bliler, Gold Rush Cure

The 2021 Bob Piniewski Volunteer-of-the-Year Award went to Jeremy Bliler for his amazing work transitioning CAC2 from an outdated database to Salesforce, including a complete data integration, all while putting the finishing touches on the CAC2 website refresh and building out the new Member Hub (Members.cac2.org) that we have dreamed of for years. Thank you, Jeremy!

The 2021 CAC2 Annual Summit was a robust two-day virtual event reflective of CAC2 values and mission, and a testament to the vigor and agility of our talented teams. The Summit provided top-notch educational programming, with multiple opportunities for members to connect and engage. Our two-day program highlighted the opportunities and plans that we and our community partners have that put children and teens with cancer first as we ready for a post-pandemic world.

Our first day featured sessions welcoming new members, our traditional Members Business Meeting, and Interest Group break out rooms. We also had a chance to meet and get to know our new Managing Director, Mandy Spielvogle Powell. We are particularly pleased to welcome Mandy to CAC2.

The virtual setting afforded the opportunity for everyone attending to contribute to our popular World Café to start the second day of the Summit. After that we enjoyed a lively set of speakers:

- The Transition to Adulthood: Health Care Responsibilities after the Childhood Cancer Experience
- An Update on the Psychosocial Standards of Care for Pediatric Cancer Patients
- Attracting and Keeping the Public's Attention: A Journalist's Advice
- Our Featured Panel: The Pediatric Oncology Drug Development Experience through the Lens of Firms that are Putting Kids First

We extend our deepest gratitude to all the attendees, presenters, and sponsors for their support and participation in 2020 and 2021 Annual Summits. We would like to acknowledge the outstanding efforts of the Meeting Team, Interest Group Leads, and all the volunteers who worked tirelessly to ensure the success of these events.



PROJECT INCUBATOR

The CAC2 gateway to growing collaborative projects to serve the childhood cancer community.

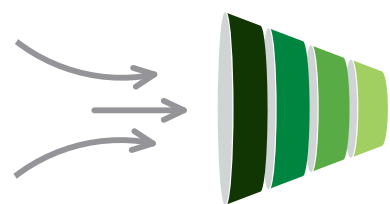
8 for 8! One of the main ways that CAC2 supports the childhood cancer community is by identifying and completing projects that individuals or organizations can't complete and manage as easily or as effectively alone. CAC2's Project Incubator is the gateway for larger collaborative projects that help advance our service to and impact on the childhood cancer community.

In our first eight years, eight projects have been selected, developed, and completed through the Project Incubator. Our 2016 Research Conference is one example of a member initiated, member-driven project identified, nurtured, and completed through this process. We are delighted to update you on the most recent successful Project Incubator Project, the Ethics Think Tank.

ETHICS THINK TANK:

An update on a current Project Incubator initiative

Non-profit organizations play a key role by funding essential research in early-phase pediatric oncology clinical trials. At the same time, families facing pediatric cancer turn to those same organizations to identify relevant research and the latest treatments for their children. Interestingly, this creates a dilemma for even the savviest of organizations, as they work to balance the interests and priorities of their donors, families, and the researchers they support. Organizations need a means to identify conflicts of interest, evaluate the scientific and ethical quality of research proposals, and ensure the trials they fund address the research needs and priorities of the communities they serve.



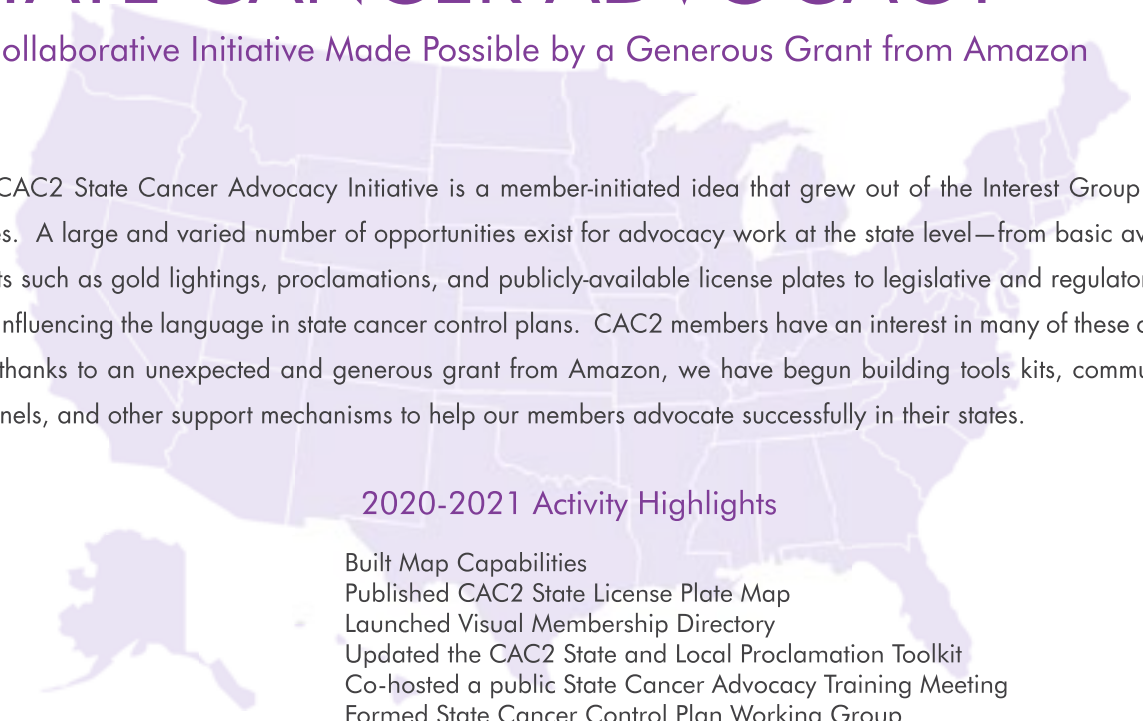
7,397 Studies Imported for Screening
5,119 Studies Screened
214 Full-Text Studies Assessed for Eligibility
54 Studies Included in Developing Paper

The Ethics Think Tank, consisting of seven CAC2 volunteer members and a bioethicist from Stanford University, undertook an academic literature review that showed little research into the specific ethical issues that advocacy organizations face. The need for a working paper outlining best practices and a template for charities to deploy was clear. The group has screened 5,119 studies, and selected 54 of those studies for inclusion in their work. The team is currently developing the paper and submitting abstracts to several pediatric oncology conferences.

STATE CANCER ADVOCACY

A Collaborative Initiative Made Possible by a Generous Grant from Amazon

The CAC2 State Cancer Advocacy Initiative is a member-initiated idea that grew out of the Interest Group Summer Series. A large and varied number of opportunities exist for advocacy work at the state level—from basic awareness efforts such as gold lightings, proclamations, and publicly-available license plates to legislative and regulatory efforts and influencing the language in state cancer control plans. CAC2 members have an interest in many of these activities, and thanks to an unexpected and generous grant from Amazon, we have begun building tools kits, communication channels, and other support mechanisms to help our members advocate successfully in their states.



2020-2021 Activity Highlights

- Built Map Capabilities
- Published CAC2 State License Plate Map
- Launched Visual Membership Directory
- Updated the CAC2 State and Local Proclamation Toolkit
- Co-hosted a public State Cancer Advocacy Training Meeting
- Formed State Cancer Control Plan Working Group
- Aggregated Model Language Compendium



BETTER TOGETHER

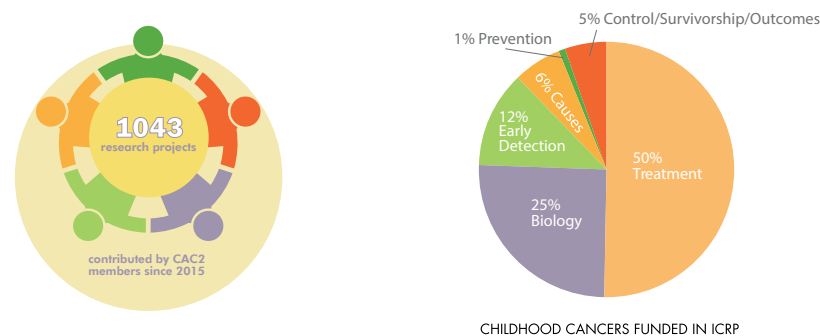
Helping survivors and their families navigate the support landscape



- Phase 1: Creation of a database of organizations offering services and resources for childhood and adolescent cancer survivors, caregivers, and organizations. This new database currently includes over 125 organizations.
- Phase 2: Creation of a "navigator" program offering stakeholders a personalized path to locate supporting nonprofit organizations in the database. This phase is currently submitted to the Project Incubator.
- Phase 3: Encourage organizations to create learning opportunities centered around survivorship services. Increase the number of survivorship organizations on the Hope Portal and the Better Together database.
- Phase 4: Facilitate and promote nonprofit partnership with Momcology and Imerman Angels to develop peer support programs for survivors and caregivers.

Supporting childhood cancer survivors and their caregivers by providing them with relevant resources and services is extremely important as they deal with the challenges of survivorship. Coordinated action and collaboration are key CAC2 principles that we want to harness with this project because we truly believe we are all "Better Together."

CAC2 joined the International Cancer Research Partnership (ICRP) in 2015. The ICRP is a global alliance of cancer research organizations, and its database houses more than 118,000 grant records for cancer research from 154 international funding organizations. CAC2 members submit funded research projects on an annual basis, and these projects represent over 1,043 projects and more than \$175M in research funding from 29 member organizations. With the addition of CAC2 to the partnership, the ICRP subsequently applied a retroactive search code for childhood cancers.



CAC2's participation in the ICRP has led to 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 CYA cancer and survivorship funders.

Global Webinar Hosted by CAC2, ICRP, and NCRI

Collaboratively with the ICRP and the National Cancer Research Institute (NCRI), CAC2 hosted a webinar for the international community entitled "How Collaboration is Advancing Research and Clinical Care in Pediatric Cancer," Co-Chaired by Amy Weinstein, CAC2 and PBTF. Vickie Buenger, CAC2, and Professor Gilles Vassal, ACCELERATE, presented how their respective organizations have changed the word of collaboration from more than just a 'buzz word' to an operating assumption and is changing the playing field for research and clinical care for pediatric cancer through multi-disciplinary and international cooperative efforts.

Report Accepted at SNO 2021

In 2020, the ICRP project committee issued a Childhood Cancer Research Funding Report titled "Trends in International Investment in Childhood, Adolescent and Young Adult (CYA) Brain Tumor Research 2006 - 2018, with a Focus on Diffuse Intrinsic Pontine Glioma." The preliminary findings from this study have been accepted for presentation at the Annual SNO meeting in November 2021 and a paper is currently under development.

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.



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