



2018-2019 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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Welcome to

Northwestern
Memorial

PRESIDENT'S MESSAGE

Members and Friends,

I'd like to welcome our new members. In the last year we have added fourteen new Member Organizations, eight new Individual Members, five new Student Members, and four new Supporting Organizations to our membership. I'd also like to thank our faithful renewing members! Together we have accomplished much, and with our vision for the future; the possibilities grow each day.

CAC2 strives to bring together organizations and individuals from the childhood cancer community to collaborate on activities and initiatives within our foundational pillars: Awareness and Advocacy Support, Research and Treatment, and Family Support and Survivorship. When we surveyed our members this year, they reaffirmed the value they receive from joining CAC2: the opportunity to learn from each other, to collaborate effectively, and to have a broader impact in the childhood cancer community.

Chance to Learn—Through our bimonthly webinar series, we give our members access to the latest information from top research scientists and thought leaders from around the country and the world. In addition, our Survivorship Working Group launched a new initiative, the Survivorship Matters blog, that probes the challenges and available resources for our survivors. We also updated the oft-cited Childhood Cancer Fact Library, which provides members and the wider community with a common set of well-sourced facts, figures, and statistics about childhood cancer.

Effective Collaboration—Having completed our seventh of seven collaboration projects with the launch of the Hope Portal last June, this year our members endorsed an eighth project: a think tank initiative exploring the issues and best bioethical practices for organizations funding research. In addition to creating a collaborative environment internally so that our members can discover ways to work together, we continued to be a source of connectivity in the community, for example co-hosting activities like the Golden Toast reception in Washington DC during Childhood Cancer Awareness month and a community-wide Twitter Town Hall on pediatric brain tumors.

Broad Impact—We also provided our members numerous opportunities to participate in coordinated social media campaigns, including a major push to illuminate landmarks and public buildings throughout September, support of International Childhood Cancer Day in February, and taking the lead on a national childhood cancer anti-bullying PSA in April. Our efforts yielded major legislative appropriation success: with \$30 million in support of the STAR Act making it into the 2019 federal budget. We continue to work to involve our members in rewarding volunteer roles and have represented the childhood cancer community at countless meetings and conferences, making sure that children and adolescents have standing when decisions about research, treatment, care, and funding are considered.

The pace has quickened in our community. We have had some legislative successes that can make a real difference for our community. Industry is increasingly activated to develop therapies for our children and AYA patients. The President elevated childhood cancer to a national priority in his State of the Union message. As we prepare for our future together, informed by our members and guided by our strategic plan, we hope to honor the trust our members place in us to pursue shared goals and build credibility as a trusted partner in the community.

With everlasting appreciation for the initiative, energy, and imagination of our members,

Vicki



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



CAC2 exists to ensure that the childhood cancer community benefits from greater levels of coordinated action and collaboration. Our more than 100 organizational members and 65 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 and Advocacy Support, Research and Treatment, and 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.

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.



We envision a world
without childhood cancers.

Working together, we can help
advance the cause so that one day,
no child will die of cancer.



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 support, and research & treatment.

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.

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
Individual Member

Kim Buff, Membership Lead
Momcology

Joy Cruse, Meetings Co-Lead
TeamConnor Childhood Cancer Foundation

Ginger Diamond, Vice President & Meetings Co-Lead
Childhood Cancer Awareness Group of Coffee County

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

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

Donna Ludwinski, Professional Meetings & Speaker Liaison
Solving Kids' Cancer

Kyle Matthews, Secretary & Technology Lead
Beat Nb

Steven L. Pessagno, Treasurer
Individual Member

Tom Pilko, Nominating Chair
Individual Member

Neal Rourke, Awareness Group Liaison
Individual Member

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

Sound fiscal oversight in all that CAC2 undertakes is as highly prioritized as the fundamental aspects of our mission.

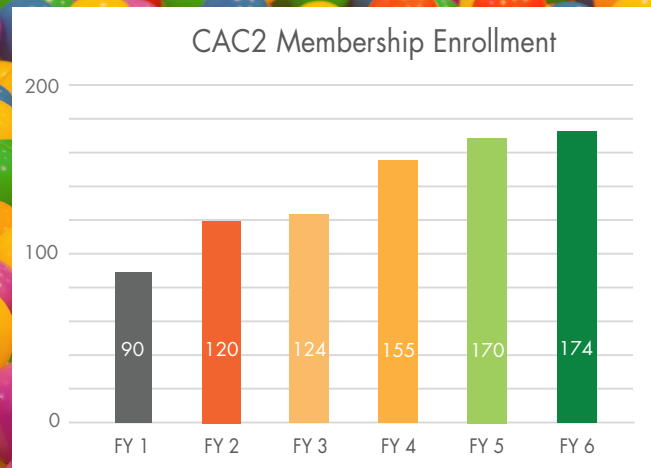
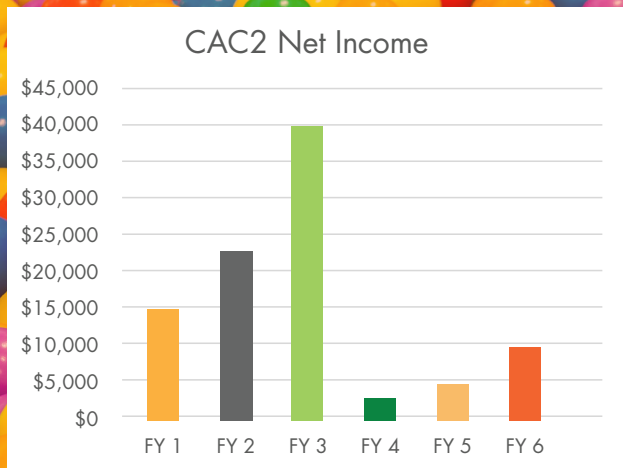
In February 2019, the CAC2 Board of Directors met for two days to revisit and revamp our strategic plan to ensure focus and sustainability for a bright future of collaboration across the childhood cancer community in shared service of pediatric cancer patients, survivors, and their families. The strategy for this bright future will focus our resources on:

- Facilitating member collaboration
- Amplifying the voice of the childhood cancer community
- Aggregating and connecting information and resources from and to our members
- Serving as a trusted partner for the community
- Preparing for scalability and long-term impact

As CAC2 begins its 7th fiscal year, it does so with a solid financial footing able to support a more expansive strategy and agenda. The factors responsible for the positive financial health of CAC2 include:

- Stable membership base with a high renewal rate year on year (80-85%);
- Grant support for specific collaboration initiatives to help defray their costs;
- Increasing amount of unsolicited grassroots donations to CAC2; and
- Disciplined management of operating expenses.

As the graphs on the next page show, CAC2 took in significantly more revenue than it paid out in expenses in its early years, primarily due to conservative expense management. Also, the sponsorship program for the research conference at Cold Spring Harbor Laboratories in Fiscal Year 3 proved particularly strong.



With more predictability in CAC2's revenue base, the Board of Directors appropriately began to increase investment in operational support for CAC2, participation in key meetings to forge deeper connections with stakeholders, and relaunching the Hope Portal. As a result of our investment in the organization's operations and influence, the positive variance in operating income has decreased in the past few years; yet CAC2 has managed its operating budget to a positive variance each year so far – and will continue to practice disciplined financial oversight to ensure sustainability.

A positive trend worth highlighting this year:
Member Support (beyond dues) has grown to nearly 40% of our donation revenue.

CAC2 members account for an increasing amount of philanthropic support to CAC2 above their membership dues. Although CAC2 members account for only 5% of the number of donations/grant received this year, they account for 40% of donation/grant revenue. There has also been a notable increase in grassroots donations via community-based fundraising – doubling from the previous fiscal year. This support is a result of CAC2 members' efforts, such as the 5th Annual Erin's Dream Race (in loving memory of Erin Buenger), individual member Mary Beth Collins raising awareness through a celebration of survivorship of her son Josh, and a variety of members' personal fundraisers on Facebook. Trends like this are heartwarming, because they indicate the positive extent to which CAC2's mission – and how CAC2 works to fulfill that mission collaboratively – resonates with nonmembers and members alike.

As always, CAC2 is especially grateful for the volunteerism of its dedicated membership and Board of Directors as well as the philanthropic support of its partners and contributors. We rely on the donations of people's time, energy, and skills, as well as financial support to deliver our mission. We thank everyone who has believed in CAC2 throughout its first six years and has enabled our membership to achieve "7 for 7" in delivering projects in our foundational pillars of Awareness and Advocacy, Family Support and Survivorship, and Research and 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





SUPPORT

CAC2 extends heartfelt gratitude to the individuals, organizations, and companies that provided charitable support to CAC2 in our 2018-19 fiscal year.

CAC2's all-volunteer leadership team and diverse members are the heart of the organization and the reason for its continued existence and achievements. While our tireless efforts and unwavering passion have produced many outcomes and have made an undeniable impact on the childhood cancer community since the inception of CAC2, we know we have much more to accomplish.

CAC2 relies on the generosity of for-profit corporations, non-profit organizations, and individuals to help advance its mission, particularly because membership dues only cover approximately half of our operating budget. Such

philanthropy is critical for enabling CAC2 to invest in new collaborative projects designed to cause positive impact for kids with cancer and their families well into the future.

CAC2 supporters make a difference for the 43 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.



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 2018-19



SUPPORT

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



2019 Annual Summit Sponsors

Functional Formularies
Genentech
Nationwide Children's Hospital
Northwestern Mutual – Kemelgor
Financial Group
Novartis*

Sustaining Supporters (\$500+)

Digital Science & Research Solutions
Erin's Dream Lanyards
Erin's Dream Race
GlaxoSmithKline Foundation
Andrea Needham
Northwest Indiana Cancer Kids
Foundation (NICK Foundation)*
Steven L. Pessagno*
Richard Plotkin*
Steven G. AYA Cancer Research
Fund*
The Parents Network/Parents
Magazine (Meredith Corporation)

General Support for CAC2's Mission

Individuals

Fran Andrews
Mike Aquino
Joanne J. Bates
Allison Brice
Walter and Vickie Buenger*
Mary Beth Collins*
Mary Jo Collins
Dale Davis
Carmella and George C. Edwards
Edward K. and Marilyn Evans
Marylou Finch
Jesse D. and Rosa A. Gage
Gene and Sandy Gerner
David and Becky Hancock
Ronald Katims
Beatrice Kerridge
Mary McCafferty
Allison Meluskey
Marcia Miculek*
Laura J. Navarro
Jeffrey S. and Lori A. Novogad
Justyne Nguyen

M. Bookman and Florence Peters
Cherilyn Renee and Christopher Brian Porter
Fedik Rahimov
Carleen Rufo Miller*
Diane B. and Dennis D. Schafer
Anne Siebold
John C. and Jan B. Taylor
Herbert T. Woods
Ernie and Marilyn Wright
Lucinda Wright

Corporations and Philanthropic Organizations

AbbVie
AmazonSmile Foundation
Make Some Noise: Cure Kids Cancer Foundation*
Network for Good (60 donations via Facebook)
PWC Community Fund
Robert Connor Dawes Fund
Vanguard Community Fund

*denotes CAC2 member





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 “Childhood Cancer Fact Library” full of sharable information, please visit cac2.org/childhood-cancer-fact-library/



Cancer is the number one cause of death by disease among children.¹

The incidence of childhood cancer is on the increase, averaging 0.6% increase per year since mid 1970's resulting in an overall increase of 24% over the last 40 years.²

43 children per day, or 15,780 children per year are expected to be diagnosed with cancer.²

1 in 285 children was diagnosed with cancer in 2014.²

Childhood cancer is not one disease – there are more than 12 major types of pediatric cancers and over 100 subtypes.²

Since 1980, only four drugs have been approved in the first instance for use in children. Fewer than eight total drugs, consisting of the three above and five others 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.³

On average, about 17% of children die within five years of diagnosis. Among those children who survive to five years from diagnosis, 18% will die within 30 years of diagnosis.⁴

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

Those who survive the five years have an eight times greater mortality rate due to the increased risk of liver and heart disease and increased risk for reoccurrence of the original cancer or of a secondary cancer.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

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 either the cancer or more commonly, the result of 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.⁸

Symptoms of post traumatic stress disorder are well documented for parents whose children have completed cancer treatment.⁹

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.¹⁰

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

2 American Cancer Society, Childhood and Adolescent Cancer Statistics, 2014 <http://goo.gl/y5RXyv>

3 National Cancer Institute, <http://www.cancer.gov/research/areas/childhood>

4 Journal of the National Cancer Institute “Cause-Specific Late Mortality Among 5 Year Survivors” <http://jnci.oxfordjournals.org/content/100/19/1368.full>

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

6 Journal of the National Cancer Institute “Cause-Specific Late Mortality Among 5 Year Survivors” <http://jnci.oxfordjournals.org/content/100/19/1368.full>

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

8 St. Jude Children's Research Hospital, (JAMA. 2013;309 [22]: 2371-2381) <http://jama.jamanetwork.com/article.aspx?articleid=1696100>

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

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



MEMBERSHIP

CHILDHOOD CANCER ORGANIZATION MEMBERS

Addison Bryan Foundation Raleigh, NC	Children's Cancer Research Fund Minneapolis, MN	Journey4ACure Broadlands, VA
Aiden's Army Eustis, FL	Children's Cause for Cancer Advocacy Washington, DC	Julia's Grace Foundation Royersford, PA
Alex's Lemonade Stand Foundation Bala Cynwyd, PA	Christina Renna Foundation Lindenhurst, NY	Ladybug House Seattle, WA
Along Comes Hope San Luis Obispo, CA	CURE Childhood Cancer Atlanta, GA	Little Eric's Foundation Pittston, PA
Amanda Hope Rainbow Angels Phoenix, AZ	Cure 4 the Kids Foundation Las Vegas, NV	MACC Fund (Midwest Athletes Against Childhood Cancer) Milwaukee, WI
Andrew McDonough B+ Foundation Wilmington, DE	Cure4Cam Childhood Cancer Foundation Lyndell, PA	Make Some Noise: Cure Kids Cancer Foundation Morristown, NJ
aPODD Foundation London, England, UK	CureSearch for Children's Cancer Bethesda, MD	Mattie Miracle Cancer Foundation Arlington, VA
Arms Wide Open Childhood Cancer Foundation Marlboro, NJ	Designing Dreams Beaver Dam, WI	Max Cure Foundation Englewood Cliffs, NJ
ASK Childhood Cancer Foundation Richmond, VA	Dragon Master Foundation Kechi, KS	MIB (Make It Better) Agents Barnard, VT
Be Strong, Fight On! Redmond, WA	Elaine Roberts Foundation Alabaster, AL	Momcology Saint Johns, FL
Bear Necessities Pediatric Cancer Foundation Chicago, IL	Emily Whitehead Foundation Philipsburg, PA	Morgan Adams Foundation Denver, CO
Beat Nb Tampa, FL	End Kids Cancer San Luis Obispo, CA	Mystic Force Foundation North Miami Beach, FL
Books That Heal Kearny, NJ	Evan's Victory Against Neuroblastoma Foundation Germantown, MD	Neuroblastoma Children's Cancer Society Hoffman Estates, IL
Braden's Hope for Childhood Cancer Olathe, KS	Fabulous Faith's Foundation Grand Prairie, TX	No More Kids with Cancer Media, PA
Brooke's Blossoming Hope for Childhood Cancer Foundation Corpus Christi, TX	For A Day Foundation Brooklyn, NY	Noah's Bandage Project Olathe, KS
Caleb's Crusade Against Childhood Cancer Ft. Myers, FL	Friends of Cathryn Foundation Laguna Beach, CA	Northwest Indiana Cancer Kids Foundation Schererville, IN
Cancer Families United Kalamazoo, MI	Gavin's Galaxy Houston, TX	Pediatric Brain Tumor Foundation Asheville, NC
CancerFree Kids Loveland, OH	Gold in September Charitable Trust Delafield, WI	Pediatric Cancer Foundation Mamaronek, NH
Candlelighters Childhood Cancer Foundation of the DC Metro Area Merrifield, VA	Gold Rush Cure Foundation Laguna Niguel, CA	People Against Childhood Cancer Wilmington, NC
Candlelighters of New York City New York, NY	Hugs for Brady Foundation Kendall Park, NJ	Precious Jules Childhood Cancer Foundation Old Bridge, NJ
Canines-N-Kids Foundation South Riding, VA	I Care I Cure Childhood Cancer Foundation Davie, FL	Richi Childhood Cancer Foundation Brookline, MA
ccTHRIVE Shelburne, VT	Jack's Angels Foundation Santa Clarita, CA	Ryan's Case for Smiles Wayne, PA
Childhood Cancer Awareness Group of Coffee County Douglas, GA	Jeff Gordon Children's Foundation Charlotte, NC	Sammy's Superheroes Columbus, NE
Childhood Cancer Guides Bellingham, WA	Jeremy Cares Avon Lake, OH	SebastianStrong Foundation Miami Springs, FL
	Joedance Film Festival Charlotte, NC	Solving Kids' Cancer New York, NY
	Joey's Wings Foundation San Diego, CA	Sophia's Fund Marlborough, MA



CAC2 members hail from many states and several countries. They include childhood cancer organizations, survivors, and advocates who support children with cancer and their families. They join CAC2 for myriad reasons. Many have experienced childhood cancer first- or second-hand. Our members often express appreciation that CAC2 effectively advances a variety of childhood cancer causes by unifying the childhood cancer community and giving them the opportunity to learn from each other, to collaborate effectively, and to have a broader impact.

To learn more about CAC2, become a member, and/or support the organization, please visit CAC2.org.

INDIVIDUAL MEMBERS

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
Team Hailey Hugs
Bethel, ME
TeamConnor Childhood Cancer Foundation
Dallas, TX
Tennessee Cancer Consortium/
Childhood Committee
Nashville, TN
The Get Well Gabby Foundation
Oceanview, DE
The Grayson Saves Foundation
Hockessin, DE
The Lilabeau Foundation For Pediatric
Cancer Research
Silver Spring, MD
The Ross K. MacNeill Foundation
Chicago, IL
The Taylor Matthews Foundation
New York, NY
The Truth 365
Marlboro, NJ
The Truth 365 - Australia
Al dingo Beach, SA, Australia
This Star Won't Go Out
Quincy, MA
Turn It Gold
Houston, TX
Ty Louis Campbell Foundation
Carmel, NY
Wade's Army
Belle Mead, NJ
West Virginia Kids Cancer Crusaders
Charleston, WVA
With Love Charity, Inc.
Jacksonville, FL
With Purpose
Charleston, SC
Zoe4Life
Gland, Switzerland
1 Makes a Difference Foundation
Columbus, OH
3/32 Foundation
Boonville, NC

Melissa Alderfer
Media, PA
Greg Aune
San Antonio, TX
Joe Baber
Virginia Beach, VA
Amelia Baffa
Wickliffe, OH
Vickie Buenger
Bryan, TX
William Burns
Lavallette, NJ
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
Karla Flook
Fort Collins, CO
Judy Fulmer
Marion, SC
Amanda Griffin
Aldinga Beach, Australia
Kevin J. Kane
Philadelphia, PA
Warren Kibbe
Chapel Hill, NC
Deborah Kochevar
Grafton, MA
Matuez Koptyra
Philadelphia, PA
Angela Lee
Schertz, TX
Maureen T. Lilly
Takoma Park, MD
Camille Loccisano
Brooklyn, NY
Robert Michael Madonna
West Chester, PA
D. Lee Marchiano
Nipomo, CA

Hannah MacIntosh
Cumming, GA
Charlene Mersburgh
Kailua Kona, HI
Marcia Miculek
Bryan, TX
Elise Morgan
Southampton, NJ
William Murray
Austin, TX
Javad Nazarian
Washington, D.C.
Hannah Neff
Berkeley, CA
Laurie Orloski
Douglassville, PA
Steven L. Pessagno
Philadelphia, PA
Joan Pilko
Berwyn, PA
Tom Pilko
Berwyn, PA
Barbara Polo
Staten Island, NY
Ram Mohan Ram Kumar
Rochester, NY
Brian Riggs
Mickleton, NJ
Neal Rourke
Desboro, ONT, Canada
Carleen Rufo-Miller
Rydal, PA
Nicoletta Sacchi
North Potomac, MD
Sheri Sallee
Omaha, NE
Tim Schmelz
International Falls, MN
Kelley Sharp
Raleigh, NC
Raquel Sitcheran
College Station, TX
Jeffrey Skolnik
Malvern, PA
Susannah Koontz Webb
Houston, TX
Batula Zaida
Chicago, IL

SUPPORTING ORGANIZATIONS

Animal Cancer Foundation
Norwalk, CT
Association of Pediatric
Hematology/Oncology Nurses
Chicago, IL
Bristol-Myers Squibb
Lawrenceville, NJ
Elephants and Tea
Shaker Heights, OH
GlaxoSmithKline
Collegeville, PA
HealX
Cambridge, England, UK
KBI Biopharma
Durham, NC
Loxo Oncology, a wholly-owned
subsidiary of Eli Lilly and Company
Stamford, CT
Notable Labs
Foster City, CA
Novartis
East Hanover, NJ

STUDENT MEMBERS

Matt Buff
Saint Johns, FL
Catherine Chester
Columbus, OH
Maddie Curtis
Oak Hill, VA
Linnie Davis
Douglas, GA
Christina Gonzales
Modesto, CA
Kelsey Leong
Manassas, VA
Nicole Lyons
New York, NY
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



JOIN US

Climb in and 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 with cancer. Members also experience:

- Increased information sharing
- Optimal environment for collaborative initiatives
- Access to information & resources for patient and family support
- Enhanced integration of national and grassroots advocacy efforts
- Discounted registrations at special programs
- Participation in the CAC2 Project Incubator

MEMBERSHIP CATEGORIES

Childhood Cancer Organizations

For organizations whose primary mission is focused on childhood cancer.

Individuals

For those not currently serving on the board or staff of either a childhood cancer organization or a supporting organization.

Supporting Organizations (non-voting member)

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

Student Members (non-voting member)

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



info@CAC2.org



members.cac2.org



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IMPACT

Our 2018-19 initiatives and projects reflect our members' shared goals and values put into action. We have worked to unify our members and build trust and credibility with our partners. We have provided opportunities for our broad and diverse membership to work together within our three Interest Groups, while guaranteeing that they have ample opportunity to learn, share information, and build bridges within and across the community.

We had our most active and impactful year ever in *advocacy and awareness*. We pushed for and won full appropriations for the STAR Act in 2018 and 2019 and provided substantive input into the implementation of that law. We used our collected voices to lift up childhood cancer concerns locally, nationally, and internationally. Our research group launched a new CAC2 project, the Bioethics Think Tank Project, and initiated two new working groups that may lead to future projects. We formed a third working group this year devoted to survivorship, so that our family support group can help our members reach families regardless of where they are in their cancer journey.

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-initiated activities. 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 to lift the spirit of collaboration and shared action up 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.

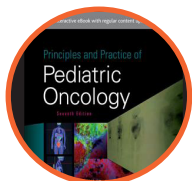


Celebrating the collaborative successes of our members and CAC2!



FDA-Approved Patient-Focused Meeting on Hearing Loss

In September, CAC2 members Children's Cause, Mattie Miracle, and Momcology collaborated to lead an open, patient-focused meeting of pharmaceutical companies, survivors, and their families as they explored the burden of chemo-induced hearing loss.



Book Chapter Collaboration

CAC2 members Susan Weiner (Children's Cause) and Vickie Buenger co-authored a textbook chapter together, "Pediatric Cancer: Advocacy and Policy Issues for Patients, Families and Survivors" in the 8th edition of Principles and Practice of Pediatric Oncology.



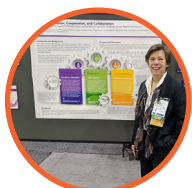
Fulfilling a Child's Dream

CAC2 members Mystic Force Foundation and Neal Rourke joined forces with the Kissimmee and Orlando Police Departments to create a dream vacation for a child with cancer. "Ryken's Big Sheriff Adventure" was a surprise to T-cell recipient Ryken.



Mother's Day Outreach

As a joint Mother's Day project this year, CAC2 members Momcology and Alex's Lemonade Stand Foundation partnered to support mothers. Momcology "took over" Alex's Twitter feed for the day and posted exciting photos and stories in support of all "momcologists" through the use of ALSF's Twitter feed and Alex's supported the distribution of 2500 gifts for "momcologists."



AACR Poster Presentation on Collaboration

CAC2 members Vickie Buenger and Julie Sutherland (Make Some Noise: Cure Kids Cancer Foundation) teamed up to create and present a poster showcasing the power of collaborative efforts in leveraging impact for the childhood cancer community.



Family Travel Support for Action Days

CAC2 members Alex's Lemonade Stand Foundation and Steven G. AYA Cancer Research Fund co-funded a travel scholarship for a Texas family to travel to Washington D.C. to advocate during Childhood Cancer Action Days.

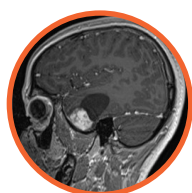


Drug Development Infographic

CAC2 members Laurie Orloski and Joe Baber pooled their knowledge and talents to create a powerful infographic demonstrating the shortfall in pediatric cancer drug development as compared to adult cancer drugs developed since 2010.

COLLABORATIVE HIGHLIGHTS

June 2018 - May 2019



Children's Brain Tumor Tissue Consortium Tumor Atlas

CAC2 member organizations Dragon Master, The Grayson Saves Foundation, No More Kids With Cancer, Swifty Foundation, the Lilabeau Foundation, and the Ross K. MacNeill Foundation worked together to support the Pediatric Brain Tumor Atlas, that compiles data from 30 types of brain tumors for open-sourced research.



Kids First Data Resource Center

CAC2 and several member organizations including Dragon Master Foundation, Alex's Lemonade Stand Foundation, the Greyson Saves Foundation, the Lilabeau Saves Foundation, No More Kids with Cancer, and Swifty Foundation supported the Kids First Resource Center's efforts to develop new, data driven strategies for treating children.



Target Pediatric AML

CAC2 member organizations Andrew McDonough B+ Foundation, Sammy's Superheroes Foundation, CURE Childhood Cancer, Jack's Angels, and Be Strong, Fight On! jointly supported a targeted co-funding opportunity where organizations can support specific projects to advance research for pediatric AML.



Bereaved Family Support

Earlier this year, CAC2 member organizations Arms Wide Open, Max Cure Foundation, Andrew McDonough B+ Foundation, Sophia's Fund, Christina Renna Foundation, and This Star Won't go Out pooled their resources to provide funeral expense support for a bereaved childhood cancer family.



Phase II Tumor Target Validation Study

CAC2 member organizations Pediatric Brain Tumor Foundation and The Taylor Matthews Foundation have a funding partnership for this target validation study for low-grade gliomas and other RAS/RAF/MEK/ERK tumors using TAK-580 (MLN2480).



ADVOCACY & AWARENESS

Pediatric Cancer Policy Roundtable
STAR Act Implementation
September Landmark and Building Illumination
International Childhood Cancer Awareness Day
Twitter Team



FAMILY SUPPORT & SURVIVORSHIP

Survivorship Matters Blog
Hope Portal Upgrade and Enhancement
Survivorship Working Group
Childhood Cancer Anti-Bullying
Public Service Announcement

CAC2

RESEARCH & TREATMENT

Bioethics Think Tank Project
International Cancer Research Partnership
Data Sharing Working Group
Improving Research Funding Collaboration Study
Group





EDUCATION

Childhood Cancer Fact Library
CAC2 Annual Summit
Curated Research Library
Webinar Series



COMMUNITY

CureFest for Childhood Cancer
The Golden Toast Reception
Twitter Town Hall on Pediatric Brain Tumors
Enhanced Relationships with Industry
Partners, Regulators, and Academics



ENGAGEMENT

Books by Members
Year Six CAC2 Membership Survey
Three-Year Strategic Plan Implementation
LinkedIn CAC2 Platform Launch

in Action



LEADERSHIP THROUGH SERVICE

CAC2 members' service on national and international review boards and advisory committees creates impact and lifts the voice of childhood cancer. Examples of CAC2 member service include:

- Pediatric Cancer Action Council
- NCI's Council of Research Advocates
- Rare Cancer Policy Coalition
- COG Disease Review Committees
- NCI PEP-CTN Agent Prioritization Committee
- ACCELERATE Working Groups



LEADERSHIP THROUGH ACTION

CAC2 members raise the visibility of childhood cancer issues by presenting at high-profile meetings, including:

- American Association of Cancer Researchers
- International Society for Biological and Environmental Repositories
- International Society of Pediatric NeuroOncology
- ICRP Partner Meeting
- American Society of Clinical Oncology
- Greehey Children's Cancer Research Institute Symposium



LEADERSHIP THROUGH EDUCATION

CAC2 wishes to thank Robin French and Joanne Salcido, the webinar team, and all of the CAC2 members who hosted presenters, as well as all of our community partners who help advance our education and information sharing mission through our bi-monthly webinar series. This year, our webinar series included the following:

- Understanding and Enhancing the Role of Children with Cancer and Their Parents in Phase 1 Clinical Trials, Stacy Crane
- Functional and Social Independence in Adult Survivors of Pediatric Brain Tumors, Tara Brinkman, PhD
- MyPART: Network for social engagement in rare solid tumors research, Dr. Karlyne Reilly
- Childhood Cancer Advocacy: National and International Voices and Action!, Ruth Hoffman and Danielle Leach
- Data Sharing: Why We Should Care About Data Sharing, Warren Kibbe, PhD
- Bright IDEAS: Problem solving technique for families facing the stress of diagnosis, treatment, and beyond, Dr. Robert B. Noll, PhD



Erin's Dream: A Legacy of Ongoing Support for CAC2



Erin's Dream Lanyards

Erin Buenger battled neuroblastoma for nearly seven years. In the last year of her life, she and her mom created lanyards to support research for childhood cancer and called the project Erin's Dream Lanyards. Erin's friends have continued her work making lanyards and other beaded items, and people all over support the project by making donations to the Coalition Against Childhood Cancer in exchange for these artful and whimsical items.



Erin's Dream Race

Erin's Dream Race began as a grassroots event in 2014 at Texas A&M University in memory of Erin. In just five years, the race which contributes 75% of race proceeds to CAC2 and 25% to Be the Match has grown into its own organization and is responsible for gathering several hundred individuals the first Sunday in March in College Station to run and walk to raise awareness for the cause.



The Coalition Against Childhood Cancer is honored to receive annual and growing support from a charity with such personal meaning.



2018 SUMMIT

Seattle Children's Hospital



2018 Distinguished Volunteer Award



Presented to Jess Kean, *Children's Cause*; Joey McMahon, *KBI Biopharma*; Vickie Buenger; and Julie Sutherland, *Make Some Noise: Cure Kids Cancer*, for their tireless dedication transitioning and re-launching the Hope Portal. Thank you!



Volunteer Award recipients not pictured: Jennifer Louis, TCCCC; Kyle Matthews, BeatNb; Joe McDonough, Andrew McDonough B+ Foundation; Diane Moore; Tom Pilko



Presenters, guests, and members at Day 1 of the 2018 CAC2 Annual Summit and Members Meeting at Seattle Children's Research Institute.

We joined CAC2 to participate in a coalition where like-minded organizations regularly meet to discuss the important legislative, treatment-related, and advocacy activities and ideas that are being undertaken by member organizations to see where we can fit in and help.

–Kelli Wright, CureSearch

CAC2 joined venue host, Seattle Children's Hospital, and presenting sponsor, Juno Therapeutics, in welcoming our attendees to Seattle for our 5th Annual Summit in June, 2018. The two-day meeting featured rich programming that highlighted the many ways we and our partners in the community have an impact on children with cancer and their families. This theme was carried throughout the speaker line-up, panels and break-out sessions, and various networking opportunities.

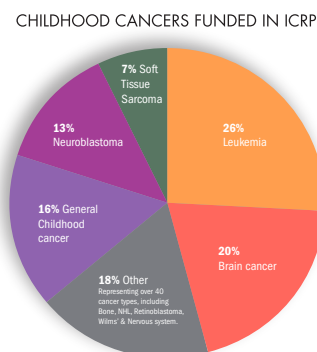
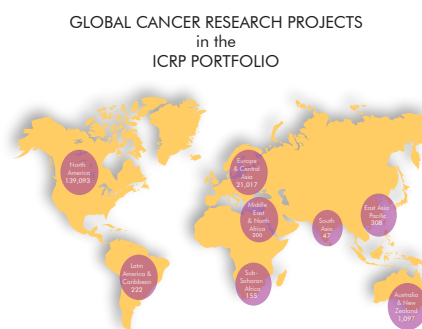
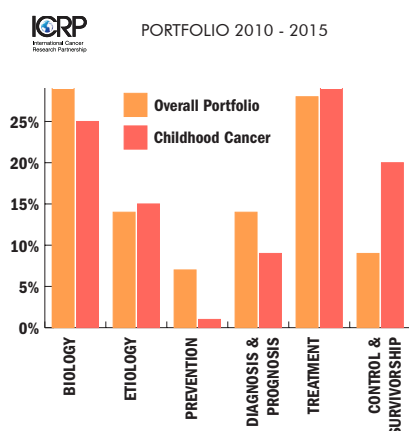
Our speaker line-up placed the spotlight on a variety of areas crucial for building progress for our community. Attendees were afforded a robust and energized opportunity to engage with experts who presented on a wide range of topics. Presenters and panelists covered the impact of immunotherapy in children's cancers, the overlap between teen and young adult cancer experiences and that of children, and ethical considerations for a child-centered approach to clinical research.

We also heard presentations related to the implementation of the community's successful advocacy efforts that addressed the implementation of both the STAR Act and impending changes to PREA. We celebrated the re-launch of the Hope Portal to serve patients and families with better access to support services.

We extend our 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, and the many volunteers who helped to make the 2018 CAC2 Annual Summit a success.

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.

The CAC2 Research Database Team convened in 2014 to explore options to fulfill aspects of the core mission of CAC2 as it relates to research funding: coordinated action, information exchange, education & learning, and broad-based collaboration. After diligent research, CAC2 joined the International Cancer Research Partnership (ICRPPartnership.org), whose database houses all types of cancer research from organizations worldwide. 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 about over 550 childhood cancer research projects funded by CAC2 members. Together we are making the database more robust and creating a more accurate view of the childhood cancer research landscape.



The partnership between CAC2 and ICRP has led to a greater understanding of the science CAC2 member organizations fund as a whole and allows members to see their data in a new way. Once submitted, data can be sliced by Common Scientific Outline (CSO) code, type of cancer, or project type, allowing organizations to see their funding strengths and opportunities. The platform also allows them to see other organizations' priorities to assess alignment and develop future potential partnerships.

Through the ICRP, CAC2 has raised the profile of childhood cancer to cancer organizations all over the world. Since join-

ing the ICRP, a unique code has been retrospectively applied to the over 80,000 projects in the database, indicating if it has a childhood cancer application to make searching for these projects easier. Data provided to the ICRP by CAC2 members contributed to a first-time analysis of the childhood cancer data set from all ICRP members. Childhood cancer funding differs from overall cancer funding by concentrating on etiology, treatment, and control/survivorship, while adult cancer research focuses on biology, prevention, diagnosis, and prognosis.

Your Gateway to Support Resources

For Childhood Cancer Patients 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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