



CAC2
COALITION AGAINST
CHILDHOOD CANCER

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Working Together Today for a Future Without Childhood Cancers



COALITION AGAINST
CHILDHOOD CANCER
cac2.org

2015 - 2016



Annual Report

Members

3/32 Foundation
 A Kids' Brain Tumor Cure Foundation
 Addison Bryan Foundation
 Alex's Lemonade Stand Foundation
 Along Comes Hope
 Andrew McDonough B+ Foundation
 Arms Wide Open Childhood Cancer Foundation
 Arya's Kids Foundation
 Amber Bannon
 Samantha Barker
 Bear Necessities Pediatric Cancer Foundation
 Because of Ezra
 David Bettoun, PhD
 Braden's Hope for Childhood Cancer
 Brooke's Blossoming Hope for Childhood Cancer Fund
 Vickie Buenger
 William Burns
 Heather Burton
 Caleb's Crusade Against Childhood Cancer
 CancerFree Kids
 Wendy Carvotta
 ccThrive
 Chase After a Cure
 Childhood Cancer Guides
 Childhood Cancer Awareness Group of Coffee County
 Children's Cause for Cancer Advocacy
 Children's Neuroblastoma Cancer Foundation
 Children's Oncology Camping Association, International
 Children's Specialty Center of Nevada
 Christina Renna Foundation Inc.
 CJ's Journey
 Mary Beth Collins
 Crosby's Fund
 Meg Lawless Crossett
 Anna Crowley
 Stephen Crowley
 MacKenzie Cruse
 Cure Childhood Cancer, Inc.
 Cure4Cam Childhood Cancer Foundation
 CureSearch for Children's Cancer
 Curing Kids' Cancer
 Maddie Curtis
 DC Candlelighters Childhood Cancer Foundation

Dragon Master Foundation
 Ethan Jostad Foundation
 Evan's Victory Against Neuroblastoma Foundation
 Faith and Grief Ministries
 Fishin' For A Cure
 Flashes of Hope
 Karla Flook
 Francesco Loccisano Memorial Foundation/Frankie's Mission
 Go Gold Fund
 Gold in September Charitable Trust
 Gold Rush Cure Foundation
 Have Faith Be Strong
 Tracy Hobiena
 Hope & Heroes Children's Cancer Fund
 Hugs for Brady Foundation
 I Care I Cure Childhood Cancer Foundation
 Jack's Angels Foundation
 Jeff Gordon Children's Foundation
 Jeremy Cares Inc.
 Journey4ACure
 Kevin J. Kane
 Kids' Cancer Research Foundation
 Kids v Cancer
 Deborah Kochevar
 Susannah Koontz
 Brendan Krinsky
 Raushan Kurmasheva
 Angela Lee
 Maureen T. Lilly
 Luck2Tuck Foundation
 Robert Michael Madonna
 Make Some Noise: Cure Kids Cancer Foundation, Inc.
 Making Headway Foundation
 D. Lee Marchiano
 Martin Truex Jr. Foundation
 Mattie Miracle Cancer Foundation
 Max Cure Foundation
 Max's Ring of Fire
 Melina's White Light
 Marcia Miculek
 Diane Moore
 Morgan Adams Foundation
 Payton Grace Mullinax
 William Murray
 Nathan's Hope
 National Brain Tumor Society
 Hannah Neff
 Noah's Light Foundation

Northwest Indiana Cancer Kids Foundation
 Novartis
 Open Hands Overflowing Hearts
 Laurie Orloski
 Pediatric Brain Tumor Foundation
 Pediatric Cancer Foundation (Mamornek, NY)
 Pediatric Cancer Foundation (Tampa, Fla.)
 People Against Childhood Cancer
 Steven L. Pessagno
 Lindsay Petrey
 Joan Pilko
 Tom Pilko
 PJs for Patients
 Barbara Polo
 Precious Jules Childhood Cancer Foundation
 Princesses on a Mission, Inc.
 Richi Childhood Cancer Foundation
 Brian Riggs
 Neal Rourke
 Carleen Rufo-Miller
 Ryan's Case for Smiles
 Sheri Sallee
 Sammy's Superheroes
 Jeffrey Skolnik, MD
 Solving Kids' Cancer
 Sophia's Fund
 Steven G AYA Cancer Research Fund
 Tom Stypulkoski
 Swifty Foundation
 tay-bandz, Inc.
 Team Daniella's Foundation
 Team G Foundation
 TeamConnor Childhood Cancer Foundation
 Tennessee Cancer Coalition-Childhood Committee
 The Alex Mandarin Foundation
 The Naya Foundation
 The Nicholas Conor Institute (TNCI)
 The Truth 365
 The Truth 365 - Australia
 This Star Won't Go Out
 Cynthia Van Lenten
 Robert Weker
 West Virginia Kids Cancer Crusaders
 Zoe4Life

CAC2 members hail from 34 states and 5 countries. They include childhood cancer organizations, individual members, advocates, and survivors that support children with cancer and their families. They join CAC2 for myriad reasons. Many have experienced childhood cancer first- or second-hand. Almost all have found tremendous frustration in the outrageous scarcity of – and lack of priority in – funding for research into innovative treatments for pediatric cancers. They often express appreciation that CAC2 effectively advances a variety of childhood cancer causes by unifying the childhood cancer community and minimizing duplication of effort through broad-based coordinated action and collaboration that leverages the strengths and expertise of our individual members. Throughout this report, you will read the words of CAC2 members about their motivation for joining, and taking advantage of the opportunities of membership. Their perspectives communicate eloquently what is so unique and valuable about CAC2.



**Amanda Jayne Griffin,
 The Truth 365 Australia**

I consider my CAC2 membership invaluable in my work as a national and international childhood cancer advocate. We need a childhood cancer movement in Australia. From my perspective, we should be working towards, and be aligned with, the international movement and working collectively against childhood cancer. The tools and resources offered by CAC2 provide insight and understanding about how a small organization can develop into a national presence both in the community and government. CAC2 has shown me what we can achieve collectively when we unite together and offer children affected by cancer and their families a powerful voice.

Coalition Against Childhood Cancer is exempt from Federal income tax as described in section 501(c)3 of the Internal Revenue Code. The official registration and financial information of Coalition Against Childhood Cancer may be obtained from The Pennsylvania Department of State. Registration does not imply endorsement.



Despite our very best efforts, errors may have occurred in the process of producing this report. If you notice a mistake, please accept our apologies and notify us immediately at:

CAC2
 PO Box 41913
 Philadelphia PA 19101

Attention:
 Steve Pessagno

admin@cac2.org

Childhood Cancer Facts

For 2015, the National Cancer Institute (NCI) budget was \$4.93 billion. Childhood cancer research received approximately \$198 million.



CAC2
 COALITION AGAINST CHILDHOOD CANCER

Leadership

Executive Committee

Vickie Buenger, President
 Individual Member

Trish Kriger, Vice President
 Jeff Gordon Children's Foundation

Steve Pessagno, Treasurer
 Individual Member

Lisa Towry, Secretary
 Alex's Lemonade Stand Foundation

Board of Directors

Steve Crowley, Advocacy Interest Group Liaison
 Individual Member

Joy Cruse, Meeting Committee Co-Chair
 TeamConnor Childhood Cancer Foundation

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

Beth Ann Krinsky, Membership Committee Co-Chair
 I Care I Cure Childhood Cancer Foundation

Donna Ludwinski, Membership Committee Co-Chair
 Solving Kids Cancer

Suzanne Nixon, Audit Committee Chair and Meeting Committee Co-Chair
 Noah's Light Foundation

Tom Pilko, Nominating Committee Chair
 Individual Member

Tony Stoddard, Awareness Interest Group Liaison
 Sophia's Fund

Julie Sutherland, Research Interest Group Liaison
 Make Some Noise: Pediatric Cancer Research Foundation



CAC2
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Why Childhood Cancer?

Heart disease causes more adult deaths in the US than any other illness. For children and adolescents, cancer is the number one disease killer. Approximately one child in five will not survive the battle with cancer. The majority of survivors will experience significant side effects that result from their treatments. Despite these grisly facts, only three drugs have been approved to treat pediatric cancer in the last 36 years. In fact, treatment for some children with cancer remains the same as it was in the 1970s. Pediatric-specific research will lead to better treatments, fewer side effects, and most importantly, finding cures; however, an enormous gap exists between the funding needs and the money available for childhood cancer research projects. Furthermore, the availability of resources to ease the burden on these children and their families also lags.



Childhood Cancer Facts

Cancers in very young children are highly aggressive and behave unlike malignant diseases at other times in life.



Childhood Cancer Facts

For children and adolescents under the age of 20, the average age at diagnosis is 8, with subgroup means of 5 for children aged 0 to 14 and 17 for adolescents aged 15 to 19. Contrast this with adults' average age when they receive their cancer diagnosis: 65. There are 70 potential life years lost on average when a child dies of cancer compared to 15 potential life years lost for adults.



Message from the President

Members and Friends,

With our birthday and the start of our fourth year together at hand, it seems appropriate to reflect on all that the CAC2 community has accomplished, particularly in the last year.

In November 2013, I penned my first note to you from the President's desk:

- We have galvanized a community of more than 50 organizations and nearly 20 individuals who are committed to work collaboratively in the fight against childhood cancer.
- We have finalized most of the necessary filings to establish CAC2 as a legally recognized non-profit organization.
- We have seated our first Board of Directors.
- We have launched the CAC2 website and have a working plan in place for members to initiate new projects for use to work on and support together.

In less than three years, we have almost doubled our membership to 132 organizational, individual, and student members from 34 states and five countries, and together we have accomplished much, much more. We are primed to transform ourselves from a nascent start up into a sustainable collaborative force in our community.

We continue to support our members' missions around our four pillars: Research and Treatment, Family Support, Advocacy Support, and Awareness, but have expanded, enhanced, and amplified our educational outreach in all of these areas. Stakeholders from all the crucial areas of the childhood cancer landscape attend our meetings and network with our members. We give our members opportunities to weigh in, provide input, and lend support to the key developments in childhood cancer of our time, like shaping the STAR Act or advising the Moonshot Blue Ribbon Panel.

Besides providing a conduit for information into the community and out to our various stakeholders, we have also refined our project incubator process. We have completed five of the seven incubator projects we have undertaken together, and by Election Day 2016, we will have finished them all. This includes the first ever research conference dedicated solely to pediatric cancer research, "From Bench to Bedside and Beyond," which I hope you will all attend.

Through all of this, I am humbled by the courage, tenacity, spirit, and imagination of our members. They exemplify everything that is great about our community and through our collected efforts we are working every day to create a world without childhood cancer.

Thank you for your partnership.

With unending appreciation,

Vickie

Thank You

CAC2 is grateful for the individuals and organizations that provided support throughout this year, financially through grants and donations, and services, either in kind or pro bono.

James Adair
Alex's Lemonade Stand Foundation
AmazonSmile Foundation
Fran Andrews
Bristol-Myers Squibb Company
Drs. Vickie and Walter Buenger
The Children's Hospital of Philadelphia
Suzanne Dysard
Erin's Dream Race
Marylou Finch
Genentech
Gene and Sandy Gerner
Angie Giallourakis
GlaxoSmithKline Foundation
Ira Hillman
Jaime L. Howard
Jeff Gordon's Children Foundation
Virginia Alice Johnson
Hilary Katz
David B. Kimble
Deborah and John Kochevar
Trish Kriger
Laurie Lenox
Donna Ludwinski
Katherine Luquette

Make Some Noise: Cure Kids Cancer Foundation
Verity McInnis
James A. and Cheryl L. Moreno
Northwest Indiana Cancer Kids Foundation
Steven L. Pessagno
Richard Plotkin
Carleen Rufo-Miller
Patsy Saisuwan
Jenna Saunders
Gail Schwartz
Amrita Sen
Dr. Bala and Bharati Shetty
Sun East Charitable Foundation
Vanguard Community Fund



Karla Flook
Individual Member

CAC2 encourages relationship building with all those who are involved in childhood cancer, including the various government entities. Through true collaboration, all members, including individual advocates, have a stronger voice. CAC2 collects information from the members and then disseminates it, when applicable, to other stakeholders, such as the NCI. Through this type of open communication around shared concerns, we are building strong and valuable relationships. When I began as an advocate for childhood cancer funding 14 years ago, the subject wasn't on many radars. In my experience, fellow advocates and I would have never reached out to NCI, pharmaceutical companies, or the FDA given the knowledge we had at the time. CAC2 is central to that collaboration.



Childhood Cancer Facts

There are approximately 375,000 adult survivors of children's cancer in the United States or one 1 in 530 adults ages 20-39. This number is expected to rise to 500,000 by 2020.

Looking Ahead Strategically

Last December, the CAC2 Board began an extensive strategic planning and goal-setting process geared towards ensuring healthy organizational growth and sustainable member engagement. The iterative and participatory process helped the Board align on three overarching goals, to help forward CAC2's mission and improve pillar activity: (1) improve support and involvement of members; (2) build organizationally sustainable processes, and (3) improve external communications and public engagement.

The desired outcomes from these goals include:

- Bridging, connecting, and engaging our diverse community;
- Establishing sustainability in a manner that is complimentary to, and non-competitive with, members;
- Providing value and meaningful experiences to members;
- Ensuring CAC2 is viewed as a resource to members and non-members alike.



The 2nd Annual Erin's Dream Race raised funds for CAC2. Photo courtesy of Jo Anne Bates.



Highlights

Annual Summit

Last year's Annual Summit brought together a remarkable host of CAC2 members, partners and leading pediatric cancer experts in Washington, DC. Highlights included an update on the current state of immunotherapy in childhood cancer research by Dr. Crystal Mackall, chief, Pediatric Oncology, NCI, and a panel discussion of the opportunities and challenges in drug development for pediatric cancers. Summit participation reached maximum capacity for the first time.

National Childhood Cancer Awareness Month Briefing

CAC2 was well represented at the National Childhood Cancer Awareness Month Briefing at the White House last September. Approximately half the guests at the invitation-only event were members of CAC2. Led by James H. Doroshow, M.D., deputy director for Clinical and Translational Research, National Cancer Institute, NIH, the briefing announced critical new developments that will lead to cures, including precision medicine's impact on treating children with cancer and the creation of the Pediatric Provocative Question Initiative.

Childhood Cancer Survivorship: The Consequences of Cure

Dr. Greg Armstrong, associate member of St. Jude Children's Research Hospital's Department of Epidemiology and Cancer Control, honored members when he debuted research findings from a study he authored, during a CAC2 webinar earlier this year. Using data from more than 34,000 childhood cancer survivors diagnosed and treated between 1970 and 1999, Dr. Armstrong and his colleagues found that childhood cancer survivors are now living longer, healthier lives.

Richmond International Raceway

On June 10th, CAC2 Members, Joe Baber (TNCI) and Greg Puryear (3/32 Foundation), presented a special award of appreciation from CAC2 and the childhood cancer community to Dennis Bickmeier, president of Richmond International Raceway (RIR). RIR and motorsports embraced Childhood Cancer Awareness Month in a huge way last September, from employees decked out in gold tee shirts and awareness activities to a shiny, gold finish line. Jeff Gordon told the crowd about the alarming challenges related to pediatric cancer, and children battling the disease from UVA and Children's Hospital of Richmond at VCU led spectators in the Pledge of Allegiance.



Jess Kean
Children's Cause for
Cancer Advocacy

CAC2 is invaluable to the childhood cancer advocacy community for its ability to amplify our individual voices in pursuit of our shared goals. A great example is the #StepUp social media campaign, which is a joint initiative of CAC2 and the Alliance for Childhood Cancer. This campaign has grown over the past 2 years into a sophisticated toolkit with its own dedicated website, enabling thousands of childhood cancer advocates to present a unified front in asking policymakers to #StepUp and Make Childhood Cancer a National Priority. This campaign is really representative of the work CAC2 does: It brings groups and individuals together to make our voices stronger and louder while respecting the autonomy and creativity of everyone participating. It gives us the tools we need to mobilize our network – and the freedom to do it in our own way.



About CAC2

History

The founders of CAC2 first convened in 2011 to explore ways the community could work together to raise awareness and collaborate, without duplicating the efforts of existing organizations. This grassroots movement brought together representatives of small, medium-sized, and large organizations, along with committed individuals who fight childhood cancer and provide support to the children and families affected by the disease. They hoped that by working together they could bridge some of the natural fragmentation that arises from having a diverse community of passionate advocates. Much of the strength of the community comes from the many different groups and individuals who have joined the fight. This group recognized that with greater cooperation among participants, more coordinated action and higher levels of collaboration, they could make more progress, faster.

Vision

CAC2 exists to ensure that the childhood cancer community benefits from greater levels of coordinated action and collaboration that: (1) leverage the unique strengths of its members, (2) minimize waste of precious resources and expertise, and (3) 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 member organizations and the childhood cancer community through action-oriented, member-directed projects and a variety of educational outreach initiatives.



	Grant Counts #	Grant Totals for Time Period	Average Grant Amount
Pre FY1	5	\$37,000.00	\$7,400
FY1	14	\$14,694.99	\$1,049.64
FY2	24	\$26,188.60	\$1,091.19
FY3	38	\$44,740.00	\$1,177.37

- Operating expenses for CAC2 are increasing approximately \$2,000 per year, from a base of \$30,000 in FY1. The organization continues to operate on a notably lean budget in accordance with the Board's approach to fiscal management and the overall spirit of the organization. CAC2 relies heavily on the donated time and energy of its members to facilitate collaboration across the childhood cancer community and deliver on its mission. CAC2 contracts for specific professional services in the areas of operations support, legal services, tax preparation, development support, and website hosting and management.

Looking Ahead

CAC2's leadership expects operating expenses to increase as the organization continues to develop and endeavors to amplify its impact. To support expansion beyond current levels, we will increase the amount of contracted human resource support in the areas of operations and program management to help run day-to-day activities and any newly approved initiatives.

CAC2 is fortunate to have a remarkable level of support and participation from our Executive Committee, Board of Directors and membership base – and this level of dedication will remain one of the hallmarks of the organization. To be sure, CAC2 will continue to leverage its members' expertise and diversity to accomplish our mission. Still, such donated time is not boundless. Accordingly, CAC2 will implement a development strategy to establish a sustainability fund that will help ensure the organization's viability well into the future. This fund will support members who will innovate collaboratively for the benefit of children and adolescents impacted by cancer, their families, and their health care professionals.

Childhood Cancer Facts

Childhood cancer is not one disease – there are more than 12 major types of pediatric cancers and over 100 subtypes. The incidence of childhood cancer is on the rise, averaging 0.6 percent increase per year since the mid-1970s resulting in an overall increase of 24 percent over the last 40 years.

Childhood Cancer Facts

Children's cancer affects all ethnic, gender, and socio-economic groups. Families who have faced childhood cancer, survived or lost children are often financially and emotionally ravaged. An estimated 80 million people have health insurance insufficient to cover the costs of a catastrophic illness such as childhood cancer. It is estimated that as many as 50 percent of families with children battling cancer will be forced to file bankruptcy.



Financial Report

Sound fiscal oversight in all that CAC2 undertakes is as highly prioritized as the fundamental aspects of our mission. As such, CAC2 ends its third fiscal year in stable financial condition. The organization has approximately \$107,000 in its bank account as of this report. That amount includes \$27,500 in sponsorship grants for our inaugural research conference, From Bench to Bedside and Beyond, which CAC2 will co-host with Cold Spring Harbor Laboratory this fall. CAC2's share of conference costs will be covered by sponsorship grants; however, the expenses will be realized in our fourth fiscal year, which begins July 1, 2016. In addition, currently unpaid expenses for June 2016 are estimated to be \$10,000.

	PRE-12 MONTH PERIOD	FISCAL YEAR 1	FISCAL YEAR 2	FISCAL YEAR 3	BALANCE
	1/1/15-6/30/15	7/1/15-6/30/16	7/1/16-6/30/17	7/1/17-6/30/18	
Deposits - Donations & Grants	\$ 37,000.00	\$ 14,694.99	\$ 26,188.60	\$ 44,740.00	\$ 123,018.77
Deposits - New Memberships	\$ 1,050.00	\$ 26,300.00	\$ 4,550.00	\$ 1,300.00	\$ 32,900.00
Deposits - Renewals	\$ -	\$ 4,550.00	\$ 24,050.00	\$ 25,550.00	\$ 54,150.00
Operating Expenses	\$ (8,830.20)	\$ (20,616.65)	\$ (32,076.30)	\$ (32,142.84)	\$ (102,674.99)
BALANCE	\$ 29,210.80	\$ 15,828.34	\$ 23,137.30	\$ 39,247.34	\$ 107,423.78
Operating income for Current Fiscal Year					\$ 39,247.34

CAC2 receives revenues from three primary sources:

- Revenue from new memberships
- Revenue from membership renewals
- Targeted grant requests and unsolicited donations

The Board-approved budget for Fiscal Year 3 categorizes operating expenses into four core areas:

- Administrative expenses
- Meetings
- Collaboration infrastructure/projects
- Professional services and development

Highlights:

- Revenue from new memberships and renewals has declined year-on-year by approximately \$2,000 from FY1 to FY2 and \$4,000 from FY2 to FY3, as new memberships have not offset the attrition in renewals. Specifically, the renewal rate for FY2 was 90 percent, and the renewal rate for FY3 looks to be between 75 percent and 80 percent. These renewal rates are high. Still, CAC2 plans to undertake a membership drive to continue to broaden the diversity of its membership and to maintain or grow membership/renewal revenue.
- Revenue from grants and unsolicited donations increased notably this year, driven by \$27,500 in support for the upcoming research conference. The number of unsolicited donations and grants received this year has increased, as has the average amount per donation.

Witness the Impact: Advocacy

CAC2 members are painfully aware of two important facts about children and adolescents fighting cancer: They are too young to vote and they don't possess the means to hire influential lobbyists. Our community unites to carry their messages to policymakers who have the power to make a difference. The work of Washington staffers, legislators, and regulators has a strong impact on the flow of funds into childhood cancer research, and ultimately, the survival of children and adolescents with cancer across the country. We strongly support community efforts and our member organizations' initiatives around advocacy, including the STAR Act, the Advancing Hope Act, and various appropriation measures. Major advocacy milestones in the last year include, but are not limited to:

The Policy Roundtable and the STAR Act

Last year, CAC2 collaborated with the Alliance for Childhood Cancer and other advocates from around the country to establish the Childhood Cancer Roundtable. Following many months of intense work, a potentially powerful document was born. That document became the Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act of 2015, which "would expand opportunities for childhood cancer research, improve efforts to identify and track childhood cancer incidences, enhance the quality of life for childhood cancer survivors, ensure publicly accessible expanded access policies that provide hope for patients who have run out of options, and make permanent the inclusion of pediatric representation on the National Cancer Advisory Board."

Michael McCaul (R-Tex.), Chris Van Hollen (D-Md.), and Jackie Speier (D-Calif.) introduced the STAR Act (H.R. 3381) in the House of Representatives, and Jack Reed (D-R.I.) and Shelley Moore Capito (R-West Va.) launched the same bill (S. 1883) in the Senate. This legislation has become a major focus of advocacy across the childhood cancer landscape. As of June 2016 a majority of the US House of Representatives and a significant number of Senators had signed on as co-sponsors. To facilitate childhood cancer advocates' influence with those in Congress, CAC2 and the Alliance created the #StepUp campaign to make childhood cancer a national priority.

Cancer Moonshot Initiative

When President Barack Obama announced the launch of the National Cancer Moonshot Initiative to accelerate cancer research during his 2016 State of the Union address, CAC2 responded with energy and enthusiasm. Through CAC2, members provided cancer research ideas to the Blue Ribbon Panel of the Moonshot Initiative, which is the group of scientific experts scrutinizing the ideas of researchers and funders who are working toward childhood cancer cures, and to the Pediatric Cancer Working Group. This opportunity arose from the relationship-building between CAC2 and the White House and also with NCI that we have cultivated over the last three years.

Childhood Cancer Facts

Some 60 percent of children who survive cancer suffer moderate to serious, often life-limiting late-effects, such as infertility, heart failure and secondary cancers.





Joe McDonough
The Andrew McDonough
B+ Foundation

In part because of the many types of childhood cancer, our community tends to be very splintered. CAC2 brings all of our groups together so that we can harness the collective passion and have critical mass with one, powerful voice. Under Dr. Vickie Buenger's outstanding leadership, the vision that Bob Piniowski and several of us had years ago is truly being realized. My organization, The Andrew McDonough B+ Foundation, has co-funded research grants and collaborated on fundraising and awareness activities with other CAC2 members. Much of that would not have happened without CAC2. And, perhaps what I like most about CAC2 is that the focus is always on the kids...not egos or personal agendas.



Witness the Impact: Family Support

From extending an understanding welcome into the “club you never wanted to join” to providing on-demand data through a peerless resource, CAC2 is deeply committed to families confronting a life-altering diagnosis and/or navigating the uncharted waters of relapse. When a family confronts cancer, dozens, if not hundreds, of questions follow the shock and fear that can take hold. No matter where they are, they can turn to CAC2. A visit to our Childhood Cancer Fact Library may be the start. We also respond to the steady flow of requests for information and connections that reach us through our website and email outreach. Parents may also find their way to our Summit and Annual meetings and meet with members who have been through the same unfathomable terrain. This simple exchange of humanity and comfort is priceless to a child's parents or grandparents. Other examples of CAC2's steadfast commitment to family support over the last year include:

Education Around the First-Ever Standards of Care for Psychosocial Care

Last year marked the culmination of four years' work by childhood cancer experts and stakeholders, as the Standards of Care for Psychosocial Care for children and their families during and after cancer treatment were unveiled. CAC2 followed this process closely and educated members about the fifteen standards that are considered essential for all children diagnosed and their families, regardless of where they are treated. According to the peer-reviewed paper printed in the journal *Pediatric Blood Cancer*, the decision to establish standards was crucial. Despite extensive research regarding the psychosocial risks for children and their families during and after cancer treatment, services offered varied significantly, depending on their treatment facility. Additionally, prior to this process, there were no published, comprehensive, evidence-based standards for children and adolescents with cancer. CAC2 recognized the foundational significance of this progress and prioritized the promotion of the new standards.

Childhood Cancer Fact Library

Whether it's a parent searching for information in the middle of the night, an advocate building a case to increase funding, or a journalist looking for sound background information, all who need answers to questions about childhood cancer can turn to the CAC2.org website Childhood Cancer Fact Library. The Fact Library team regularly updates and provides citable sources for the latest statistics and information about the critical aspects of childhood cancer. This year, we added a new section on psychosocial care to help parents advocate for support that addressed the mental well-being of their children during and after their cancer treatments.

Witness the Impact: Research

Prioritizing, protecting, and growing childhood cancer research represents an urgent goal for the childhood cancer community. Every member in CAC2 recognizes that we must increase research funding substantially, and from all possible sources, to reach the vision of a future without childhood cancer. Last year, the emphasis on research at CAC2 grew through:

International Cancer Research Partnership

2015-2016 marked the second year of CAC2's participation in the International Cancer Research Partnership (ICRP). The ICRP manages a database that houses cancer research information from organizations worldwide. Previously, the database significantly underrepresented childhood cancer data. Our growing partnership has helped jump-start efforts to rectify that deficit, resulting in more data and easier search navigation for childhood cancer projects. CAC2 members have submitted information about more than 400 research projects they've funded, in excess of \$25 million. Additionally, over the last year, the ICRP has improved its search and report functions, making it easier to research in the database.

Planning From Bench to Bedside and Beyond

Over the last year, CAC2 has undertaken the creation and planning of an unprecedented collaborative forum for the full range of pediatric cancer stakeholders. From academia to government and industry to nonprofits, leading experts in emerging technologies, drug development, and the clinical landscape will identify challenges and opportunities to address unmet needs and improve outcomes in childhood cancers. Co-hosted by CAC2 and Cold Spring Harbor Laboratory, this trailblazing gathering will take place Sunday, October 30 – Wednesday, November 2, 2016.

Webinars and Other Opportunities to Leverage CAC2 Alliances

The CAC2 Research Interest Group provides members with the benefit of hearing from experts throughout the childhood cancer landscape. During the last year, members learned about a comprehensive selection of research-related issues. Recordings of these presentations are available on the CAC2 website. Among the presentations available are:

Epigenetics, Pharmacogenetics and Pharmacogenomics.

Led by **Dr. John Maris**, Giulio D'Angio, endowed professor of Pediatric Oncology at the Children's Hospital of Philadelphia and the Perelman School of Medicine at the University of Pennsylvania, this webinar reviewed the process of learning causations and mutations, as well as finding targets in childhood cancer.

Non-Profit Driven Oncology Drug Development. **Dr. Cesare Spadoni**, chairman and co-founder of London-based Accelerating Paediatric Oncology Drug Development, educated members about the power of parents and nonprofits in the process of developing innovative drugs for children with cancer. Dr. Spadoni described the new operating models and collaboration with fellow stakeholders necessary to accomplish the goal of breaking new ground in treatment and therapy for patients.

Childhood Cancer Facts

The causes of most childhood cancers are unknown and are not strongly linked to lifestyle or environmental risk factors, unlike many adult cancers. In the US, the incidence of cancer among adolescents and young adults is increasing at a greater rate than any other age group, except those over 65 years.

