



2016-2017 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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2016 Annual Summit
Children's Hospital of Philadelphia
June 22 - 23, 2016

MESSAGE FROM THE PRESIDENT



ABOUT US

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

The Coalition Against Childhood Cancer (CAC2) is a member-driven network organization with 100 plus member organizations and more than 50 individual and student members who 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. We work to share information with and among our members and to provide numerous opportunities for education within each pillar. We also promote 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 cooperation across the childhood cancer community.

We neither fund research nor support patients directly, but instead focus 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. Regardless, our members believe 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 the lives of children and adolescents affected by cancer.

Members and Friends,

I'd like to welcome our new members. In the last year we have added 23 new Member Organizations, 14 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 the possibilities grow each day.

CAC2 strives to bring together the many organizations and individuals from the childhood cancer community to collaborate on activities and initiatives within our foundational pillars: Awareness and Advocacy Support, Research and Treatment, and Family Support. Following through on the 2016 Strategic Plan, CAC2 has worked over the last year to:

- Provide valuable and meaningful experiences to our members;
- Bridge, connect, engage, and serve our diverse community;
- Create sustainable processes complimentary to, and not in competition with, our members.

This year we expanded and amplified our educational outreach. Our focal accomplishment was organizing and co-hosting *From Bench to Bedside and Beyond* with Cold Spring Harbor Laboratory, a research conference dedicated solely to pediatric cancer research. Through our webinar series, we gave our members access to the latest information from top research scientists and thought leaders from around the country and the world. We also provided our members opportunities to shape and lend support to key developments in childhood cancer policy.

Besides serving as a conduit for information to our members and out to our various stakeholders, CAC2 continues to support member-endorsed projects. The Childhood Cancer Fact Library team has incorporated the latest data, evidence, and statistics into our Fact Library, giving us a common set of facts and figures when we talk about childhood cancer. Our partnership with the International Cancer Research Partnership is yielding better reporting and tracking of sponsored childhood cancer research. We will soon launch an internal listserv to help our Family Support Interest Group members connect and support one another in their common mission to provide resources to patients and their families.

We have also taken substantial steps towards guaranteeing our efforts will continue in the future through a frugal approach to fiscal management and by strengthening relationships within and beyond our organization. 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.

Through all of this, I am humbled by the courage, tenacity, spirit, and imagination of our members. They exemplify everything that is unique and impactful about our community. Thank you for your partnership.

With unending appreciation,
Vickie

It is our greatest wish to end childhood cancer. We work together to help advance the cause so that one day, no child will die of cancer.



MISSION

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.

HISTORY

The founders of CAC2 first convened in 2011 to explore ways in which the community could work together to raise awareness and collaborate without duplicating the efforts of existing organizations. This grass roots movement brought together representatives of small, medium, and large organizations, along with committed individuals, to fight childhood cancer and provide support to children and families affected by cancer. They hoped that by working together they could bridge some of the natural fragmentation that arises from having a diverse community of passionate advocates. The CAC2 founders recognized that by encouraging greater cooperation, coordination, and higher levels of collaboration among its members, they could make more progress, faster, and with greater impact.

VISION

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 member organizations and the childhood cancer community through action-oriented, member-directed projects and a variety of educational outreach initiatives.

LEADERSHIP

Vickie Buenger, President
Individual Member

Mary Beth Collins, Communication Chair
Individual Member

Steve Crowley, Advocacy Interest Group Liaison
Individual Member

Joy Cruse, Meeting Committee Co-Chair
Team Connor Childhood Cancer Foundation

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

Trish Kriger, Vice President & Membership Chair
Jeff Gordon Children's Foundation

Donna Ludwinski, Speaker and Programs Liaison
Solving Kids' Cancer

Suzanne Nixon, Meeting Committee Co-Chair
Individual Member

Steve Pessagno, Treasurer
Individual Member

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: Cure Kids Cancer Foundation

Lisa Towry, Secretary
Alex's Lemonade Stand Foundation



MEMBERSHIP

CAC2 Members include childhood cancer organizations, individual members, advocates, and survivors. CAC2 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 members.

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

CAC2 Members hail from 34 states and 5 countries!

CHILDHOOD CANCER ORGANIZATION MEMBERS

A Kids' Brain Tumor Cure Foundation
Chappaqua, NY
Addison Bryan Foundation
Raleigh, NC
Aiden's Army
Eustis, FL
Alex's Lemonade Stand Foundation
Bala Cynwyd, PA
Along Comes Hope
San Luis Obispo, CA
Andrew McDonough B+ Foundation
Wilmington, DE
aPODD Foundation
London, England, UK
Arms Wide Open Childhood Cancer Foundation
Marlboro, NJ
Be Strong, Fight On!
Redmond, WA
Bear Necessities Pediatric Cancer Foundation
Chicago, IL
Beat NB
Tampa, FL
Bike Bald
Naperville, IL
Books That Heal
Kearny, NJ
Braden's Hope for Childhood Cancer
Olathe, KS
Caleb's Crusade Against Childhood Cancer
Ft. Myers, FL
CancerFree Kids
Loveland, OH
Candlelighters Childhood Cancer Foundation of the DC Metro Area
Merrifield, VA
Candlelighters of New York City
New York, NY
Canines-N-Kids Foundation
South Riding, VA
cc:Thrive
Burlington, VT
Chase After a Cure
Summerville, SC
Childhood Cancer Awareness Group of Coffee County
Douglas, GA
Childhood Cancer Guides
Bellingham, WA
Children's Cause for Cancer Advocacy
Washington, DC
Children's Neuroblastoma Cancer Foundation
Bloomington, IL

Christina Renna Foundation
Lindenhurst, NY
CJ's Journey
St. Charles, MO
Conquering Kidz Cancer
New York, NY
Cure Childhood Cancer
Atlanta, GA
Cure4 the Kids Foundation
Las Vegas, NV
Cure4Cam Childhood Cancer Foundation
Lyndell, PA
CureSearch for Children's Cancer
Bethesda, MD
Curing Kids' Cancer
Marietta, GA
Designing Dreams
Minneapolis, MN
Dragon Master Foundation
Kechi, KS
Elaine Roberts Foundation
Alabaster, AL
Emily Whitehead Foundation for Childhood Cancer Research
Bryn Mawr, PA
Evan's Victory Against Neuroblastoma Foundation
Germantown, MD
Flashes of Hope
Mayfield Heights, OH
Francesco Loccisano Memorial Foundation
Brooklyn, NY
Gold in September Charitable Trust
Delafield, WI
Gold Rush Cure Foundation
Laguna Niguel, CA
Have Faith Be Strong
Mountainview, CA
Hugs for Brady Foundation
Kendall Park, NJ
I Care I Cure Childhood Cancer Foundation
Davie, FL
Jack's Angels Foundation
Santa Clarita, CA
Jeff Gordon Children's Foundation
Charlotte, NC
Jeremy Cares
Avon Lake, OH
Joedance Film Festival
Charlotte, NC
Journey4ACure
Broadlands, VA
Kids' Cancer Research Foundation
San Luis Obispo, CA
Kids v Cancer
Washington, DC
Little Eric's Foundation
Pittstown, PA

Make Some Noise: Cure Kids Cancer Foundation
Morristown, NJ
Martin Truex Jr Foundation
 Mooresville, NC
Mattie Miracle Cancer Foundation
Arlington, VA
Max Cure Foundation
Englewood Cliffs, NJ
MIB (Make It Better) Agents
Barnard, VT
Morgan Adams Foundation
Denver, CO
Mystic Force Foundation
North Miami Beach, FL
Nathan's Hope
Rustburg, VA
No More Kids with Cancer
Media, PA
Noah's Bandage Project
Olathe, KS
Noah's Light Foundation
Winter Garden, FL
Northwest Indiana Cancer Kids Foundation
Schereville, IN
Open Hands Overflowing Hearts
Birmingham, AL
Pediatric Brain Tumor Foundation
Asheville, NC
Pediatric Cancer Foundation
Mamaronek, NH
People Against Childhood Cancer
Wake Forest, NC
Prayers for Elijah
Concord, NC
Precious Jules Childhood Cancer Foundation
Old Bridge, NJ
Princesses on a Mission
Windsor, NC
Richi Childhood Cancer Foundation
Brookline, MA
Ryan's Case for Smiles
Wayne, PA
Sammy's Superheroes
Columbus, NE
Sebastian Strong Foundation
Miami Springs, FL
Solving Kids' Cancer
New York, NY
Sophia's Fund
Marlborough, MA
Steven G AYA Cancer Research Fund
West Lake, OH
Swifty Foundation
Woodridge, IL
Team Daniella's Foundation
Miami, FL

Team G Foundation
Scotts Valley, CA
TeamConnor Childhood Cancer Foundation
Dallas, TX
Tennessee Cancer Consortium -- Childhood Committee
Nashville, TN
The Alexander Muñoz Memorial Fund
Oceanport, NJ
The Get Well Gabby Foundation
Oceanview, DE
The Grayson Saves Foundation
Hockessin, DE
The Scarlett Fund
New York, NY
The Truth 365
Marlboro, NJ
The Truth 365 - Australia
Azinga Beach, SA, Australia
This Star Won't Go Out
Quincy, MA
Turn It Gold
Houston, TX
Wade's Army
Wayne, PA
West Virginia Kids Cancer Crusaders
Charleston, WVA
With Purpose
Charleston, SC
Zoe4Life
Gland, Switzerland
3/32 Foundation
Booneville, NC

INDIVIDUAL MEMBERS

Joe Baber
Virginia Beach, VA
Vickie Buenger
Bryan, TX
Bobbi Burke
Columbus, OH
William Burns
Lavalette, NJ
Wendy Carvotta
Marietta, GA
Cathy Collins
Lusby, MD
Mary Beth Collins
Bel Air, MD
Casey Crossan
Oak Ridge, IL
Meg Lawless Crossett
Centerville, VA
Stephen Crowley
Washington, DC

Joseph Dudash, Jr.
Asbury Park, NJ
Erin Ewald
Indianapolis, IN
Karla Flook
Fort Collins, CO
Kevin J. Kane
Philadelphia, PA
Deborah Kochevar
Grafton, MA
Raushan Kurmasheva
Helotes, TX
Angela Lee
Shertz, TX
Maureen T. Lilly
Takoma Park, MD
Robert Michael Madonna
West Chester, PA
D. Lee Marchiano
Nipomo, CA
Marcia Miculek
Bryan, TX
Diane Moore
Raleigh, NC
Elise Morgan
Southampton, NJ
William Murray
Austin, TX
Hannah Neff
Berkley, CA
Suzanne Nixon
Celebration, FL
Laurie Orloski
Douglassville, PA
Stephen Pecevich
Boston, MA
Steven L. Pessagno
Philadelphia, PA
Joan Pilko
Malvern, PA
Tom Pilko
Malvern, PA
Barbara Polo
Staten Island, NY
Brian Riggs
Mickleton, NJ
Neal Rourke
Desboro Ont, Canada
Carleen Rufo-Miller
Rydal, PA
Nicoletta Sacchi
North Potomac, MD
Sheri Sallee
Omaha, NE

Kelley Sharp
Raleigh, NC
Raquel Sitcheran
College Station, TX
Jeffrey Skolnik, MD
Malvern, PA
Susannah Koontz Webb
Houston, TX
Lori Wecht
Clearwater, FL
Robert Weker
Wynnewood, PA

SUPPORTING ORGANIZATIONS

Animal Cancer Foundation
Norwalk, CT
KBI Biopharma
Durham, NC
National Brain Tumor Society
Newton, MA
Novartis Oncology
East Hanover, NJ
Rare Cancer Research Foundation
Raleigh, NC

STUDENT MEMBERS

Amber Bannon
Portland, OR
Samantha Barker
West Bloomfield, MI
S. Biddle
San Luis Obispo, CA
Malkiel Cohen
Cambridge, MA
Anna Crowley
Washington, DC
MacKenzie Cruse
Frisco, TX
Maddie Curtis
Oak Hill, VA
Paige DePagter
Tampa, FL
Abrienne Joseph
Wesley Chapel, FL
Brendan Krinsky
Plantation, FL
Melinda Marchiano
Nipomo, CA
Lindsay Petrey
Cumming, GA

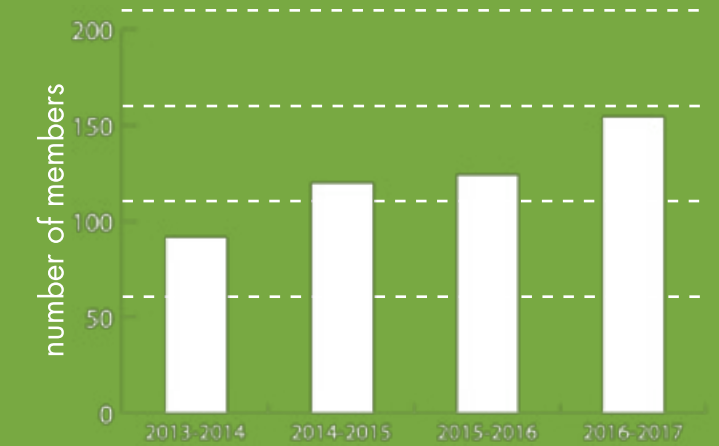




Membership Growth

CAC2 members represent a broad spectrum of people who are unified in their commitment to help eradicate childhood cancer.

Membership revenue is made up of new memberships and renewals.



FINANCIALS

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

CAC2 will end its fourth fiscal year on June 30, 2017 in sound financial position. CAC2 began Fiscal Year 4 on July 1, 2016, with \$111,287 in net assets; as of this writing, CAC2 has \$112,735 in net assets. CAC2 continues to rely primarily on the time, skills, and energy volunteered by its Board of Directors, Individual Members, and Organization Members to operate the Coalition on a day-to-day basis as well as design and implement collaborative initiatives to help make a difference for children and adolescents with cancer and for their families.

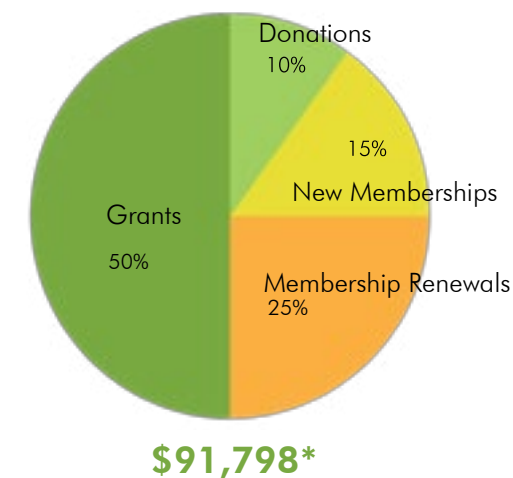
Operating expenses for CAC2 this year increased approximately 60% from the previous year, entirely accounted for by the successful pediatric research conference *From Bench to Bedside and Beyond*, which was co-hosted with Cold Spring Harbor Laboratory (Long Island, NY) in the Fall of 2016.

CAC2 is fortunate to receive grants and donations from a variety of corporations, organizations (including CAC2 Member Organizations), and individuals (both CAC2 members and not). For the third consecutive year, CAC2 was the beneficiary of proceeds from Erin's Dream Race, an event organized by Dr. Verity McInnis and students of Texas A&M University (College Station, Tex.) in loving memory of Erin Buenger, daughter of CAC2 President Vickie Buenger and her husband, Walter.

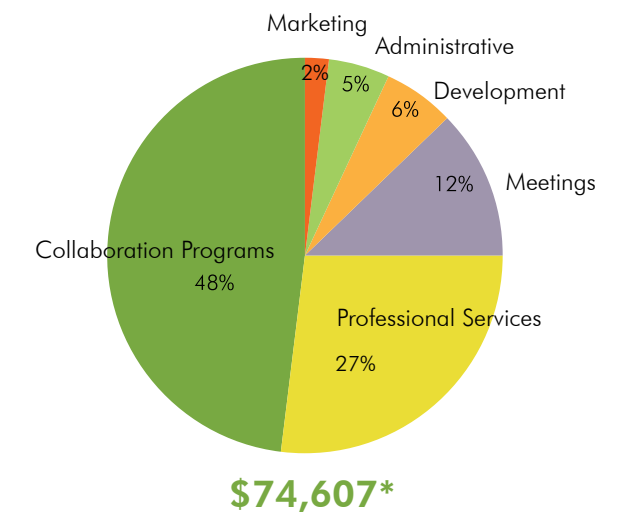
As CAC2's members seek to be more effective and efficient in funding childhood cancer research, providing services to and advocating for children & adolescents and their families, and raising greater awareness for the cause, the

2016-2017 Fiscal Year

Revenue



Expenses



*CAC2 received \$39,000 in grants in Fiscal Year 3 for the pediatric cancer research conference, *From Bench to Bedside and Beyond*, but the expenses for the conference occurred in Fiscal Year 4.

Coalition will need to be even more successful in raising funds to create opportunities and resource capacity to design and implement new, impactful collaborative initiatives to benefit pediatric cancer patients, their families, and the advocates and health care professionals who care for them.

Steven L. Pessagno
Treasurer, Coalition Against Childhood Cancer

Join Us

Whatever brings you to childhood cancer, join CAC2 and help advance the cause through cooperative efforts.

Visit: cac2.org/about-us/join-cac2



There are many benefits to joining CAC2:

The primary benefit to you is the opportunity to establish stronger relationships and increased opportunities for coordinated action and collaboration with other groups and individuals who advocate for children with cancer. Other benefits include:

- Increased information sharing
- Stronger capability to facilitate coordinated action
- Access to information & resources for patient and family support
- Enhanced integration of national and grass-roots advocacy efforts
- Optimal environment for collaborative initiatives

There are two classes of Voting Members:

Organization Membership – For childhood cancer organizations, coalitions, and nonprofit organizations with a primary interest in childhood cancer issues.

Individual Membership – For individuals (advocates, doctors, nurses, scientists, etc.) not currently serving on the board or staff of any member organization.

Non-Voting Membership Classes:

- Associate Memberships
- Student Memberships
- Supporting Organization
(organizations not primarily focused on childhood cancer)



CAC2
P.O. Box 41913
Philadelphia, PA 19101



cac2.org



info@cac2.org



SUPPORT

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



VOLUNTEER HOURS

CAC2 Members contributed an estimated 4,500 hours of manpower this year to help advance our mission.
THANK YOU!



SUPPORTERS

We are head-over-heels for our supporters!

CAC2 wishes to extend its deepest gratitude to all of our generous supporters in 2016-2017

With sincere gratitude, CAC2 acknowledges the following corporations, non-profit organizations, and individuals for providing financial support to the Coalition either in the current fiscal year or for *From Bench to Bedside and Beyond*, which took place this fiscal year. Philanthropic giving to CAC2 inspires all of our members to aim higher, strive harder, and dream even bigger about what we can accomplish together for children, adolescents and their families who are impacted by pediatric cancers.

AmazonSmile Foundation
Amgen USA
Bristol-Myers Squibb Corporation
Chris Nevin
Dr. John C. and Jan B. Taylor
Erin's Dream Race c/o Dr. Verity McInnis
Ernie Dimaline
Frances B. Vick
Gene and Sandy Gerner
GlaxoSmithKline Foundation
Ignyta Inc.
Jaime L. Howard
Jo Anne Bates

Joel and Shirlene Ross
Loxo Oncology
M. Bookman and Florence Peters
Marsha and Murray Milford
Northwestern Mutual - Chicago; McQuade Financial Group, LLC
Northwestern Mutual- Dallas
PPD
Robin Brunet
Tanya Loewen
United Therapeutics Oncology
Vanguard Community Fund
Wells Fargo Community Support Campaign

CAC2 Members

Alex's Lemonade Stand Foundation
Andrew McDonough B+ Foundation
Deborah and John Kochevar
Walter L. and Vickie Buenger
Make Some Noise: Cure Kids Cancer Foundation
Northwest Indiana Cancer Kids Foundation
Steven L. Pessagno





AWARENESS AND ADVOCACY SUPPORT

- End-of-Year Legislative Push
 - Creating Hope Act re-authorized
 - STAR Act passed in the House of Representatives
- Proclamation Tool Kit
- September Activities
 - CureFest
 - White House Briefing
 - Congressional Caucus Summit



IMPACT

CAC2 exists to ensure that the childhood cancer community benefits from greater levels of coordinated action and collaboration.

Our 2016 - 17 initiatives and member-endorsed projects include our webinar series, our involvement with the International Cancer Research Partnership (ICRP) to improve tracking and reporting on funded childhood cancer research, periodic advocacy pushes, and efforts to coordinate care for families who need support. In addition, we came together this year as invigorated and inspired volunteers to plan, organize, and host a large-scale research conference covering the most prominent new technologies and clinical developments in the field: *From Bench to Bedside and Beyond* featured notable speakers and guests from across the United States and Europe. The collaborative spirit driving the meeting, co-hosted with Cold Spring Harbor Laboratory, resulted in a variety of new joint projects and also inspired this year's CAC2 Summit theme, "Building Our Future Through Shared Opportunities."

The spirit of working together permeates everything we do at CAC2. We have noticed that journalists consult and cite our Childhood Cancer Fact Library more often every year, likely owing to the regular updating and rigorous vetting that drives the information. Reporters from media outlets as disparate as Nature, Harper's Magazine, ABCNews.com, and the National Law Journal turned to CAC2 this

year as a trusted source for stories. Other stakeholders in the childhood cancer community—investigators, clinicians, industry sponsors, and regulators—increasingly seek to work with and through us to make strides against this terrible group of diseases known as childhood cancer. Our Board and our members are strengthening and expanding those relationships on a daily, weekly, and monthly basis. We represent the childhood cancer community in a variety of settings, from the Cancer Moonshot Summit, to meetings with professional associations, and forums convened by thought leaders and industry partners to contemplate the weightiest questions facing our community. In addition, we are recognized by a number of organizations as a serious convener and collector of information for our members.

Building on our foundational principles, we have begun and advanced the slow, but crucial work of bridging some of the natural fragmentation that arises from having such a diverse community of passionate advocates. As we aspire to a future without childhood cancers, we continue to work together to make a positive difference in the lives of children and adolescents, and their families, who are impacted by pediatric cancers today.



RESEARCH

- *From Bench to Beside and Beyond* Pediatric Cancer Research Conference
- International Cancer Research Partnership
- Webinars
 - A Personalized Precision Approach to Therapy for Neuroblastoma
 - The Blood-Brain Barrier
 - The Canine-Kid Connection
 - The Blue Ribbon Panel Report
 - Cavatica: The Promise of Big Data

FAMILY SUPPORT

- Family Support ListServ development
- Hope Portal upgrade initiative
- All-Member Webinar: "Helping Patients Afford Therapy"



June



The 2016 CAC2 Summit and Annual Meeting, hosted through the generosity of the Children's Hospital of Philadelphia, brought members together in Philadelphia to experience another robust speaker line-up, networking, and lab tours. | Vice President Joe Biden gathered 300 cancer experts and advocates for the National Cancer Moonshot Summit in Washington DC, including twelve CAC2 members. Two of our members participated in the small group working session with the Vice President.

July



The CAC2 Research Interest Group hosted a webinar with Dr. Adam Resnick, who presented "Cavatica: The Promise of Big Data" to educate members about an exciting new cloud-based environment for securely storing, sharing, and analyzing large volumes of pediatric genomics data.

August



We hosted an All-Member webinar featuring clinicians from the Oncology Research & Development team at Bristol-Myers Squibb. Our guest speakers provided insights on the clinical trial process from an industry sponsor's point of view.

September



In addition to their awareness efforts in September, CAC2 members were busy in DC at key Childhood Cancer Awareness Month activities, including the White House Briefing on Childhood Cancer, the Childhood Cancer Congressional Caucus Summit, and CureFest. | In addition to exhibiting at CureFest, we hosted a CAC2 Welcome reception and held interest group working meetings.

October



We hosted a webinar with Blue Ribbon Panel members Dr. Peter Adamson (COG Chair) and David Arons (CEO of the National Brain Tumor Society), who discussed the panel's report and implications for pediatric cancer. | CAC2 representatives attended the White House National Cancer Moonshot Report release event. | The Advocacy and Awareness Interest Group published a step-by-step toolkit for our community to guide officials to proclaim September as Childhood Cancer Awareness Month. | CAC2 members attended the 2016 Pediatric Oncology Workshop hosted by member organization Children's Cause for Cancer Advocacy and industry partners BIO and PhRMA.

November



CAC2 members, investigators, clinicians, industry partners, and regulators from all over the country and Europe converged on Cold Spring Harbor Laboratory to experience CAC2's two-day pediatric research conference, From Bench to Bedside and Beyond. [Read more on pages 18 - 19]

December



21st Century Cures, reauthorizing the Creating Hope Act Pediatric Priority Review Voucher Program, was signed into law. The Childhood Cancer STAR Act passed through the House unanimously, but ran out of time in the Senate. The RACE Act received promise of consideration in the next session. Many CAC2 members advocated in support of these crucial legislative efforts.

January



In January, as part of our All-Member webinar series, we provided an opportunity to our members to learn about emerging technology using ultrasound and micro-bubbles to deliver therapeutic agents across the blood-brain barrier from Vesselon executives Clay Larsen and Rhodemann Li.

February



The CAC2 Family Support Interest Group hosted a webinar on helping patients afford drugs and therapeutics, with speakers from FundMed. | The Group also began beta testing on a new group listserv to facilitate information exchange and better assist families.

March



The 3rd Annual Erin's Dream Race in memory of Erin Buenger benefitting CAC2 was run in College Station, Texas. | CAC2 members from both sides of the Atlantic attended the 5th ACCELERATE Paediatric Oncology conference in Brussels, Belgium. The program aim was to incentivize the development of new cancer treatments for children and adolescents.

April



The CAC2 Board of Directors hosted our All-Member Spring webinar to give an update on the many projects and activities involving the organization. One topic featured in the presentation was the current year's efforts to take advantage of our partnership with International Cancer Research Partnership, (ICRP). [See pediatric funded research projects analysis in ICRP on pg. 20]

May



Members traveled to DC for Childhood Cancer Action Days in May to support the STAR Act, the RACE Act, and increased funding from the NIH for basic research. | We also hosted a webinar, with physician investigators from the New Approaches to Neuroblastoma Therapy (NANT) clinical trials consortium, by Dr. Shahab Asgharzadeh and Dr. Yael Mosse.

CONFERENCE OVERVIEW

“From Bench to Bedside and Beyond”



2 Days

of mixing and mingling with advocates, funders, scientists, industry, and government representatives.



18 Speakers

from the front lines of emerging technologies and patients' bedsides. Six participated in a panel discussion on breaking down barriers.



150 Participants

engaging in a collaborative forum with the full range of stakeholders for childhood cancer.



2 Winners

chosen by popular vote at the Poster Session, to win cash prizes for their outstanding research presentations.



25 Volunteers

planning, organizing, soliciting, reviewing abstracts, proofing, promoting, editing, staffing...



14 Sponsors

very generously supporting our efforts by underwriting the meeting costs.

Together with our co-host, Cold Spring Harbor Laboratory, we united members of the childhood cancer community in an unprecedented collaborative forum to help advance the cause for childhood cancer research. We gathered at the historic Cold Spring Harbor Laboratory campus for an inspiring multi-day exchange of knowledge and networking. Looking back at the relationships forged, the connections made, and the information shared among attendees, it was a truly engaging and exciting meeting. Connecting and collaborating are key to finding the cures!

While the challenges are significant, it is abundantly clear that clinicians, researchers, and advocates in the childhood cancer community share a common “Wish List” that includes:

- Solve the challenge of small patient numbers
- Collect and analyze more preclinical data
- Encourage greater data collection and sharing
- Secure earlier and more generous access to drugs for children with cancer
- Secure earlier and more generous access to clinical trials for children with cancer
- Make needed adjustments to the clinical trial infrastructure and trial design
- Build pathways to better prioritization for pediatric-specific therapies

Moving to collective action and accelerating the pace of therapy discovery is in order. The criticality of setting up channels of communication cannot be overstated. There will be a shared responsibility among those represented at the CAC2 research conference (Researchers, Clinicians, Sponsors, Regulators, Funders, and Families) to make positive change for children with cancer a reality. The first step in the process will be to use communication and collaboration to close the gaps, creating new pathways for information exchange. The second step, even more challenging than the first, will require bridging the existing gaps in public/private partnerships.



Advocates | Funders | Researchers | Clinicians | Federal Regulators | Industry Representatives

2016 Summit and Annual Meeting

Children's Hospital of Philadelphia

June 22 - 23, 2016



Karla Flook
2016 Volunteer of the Year



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, 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 0.6% 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 three drugs have been approved in the first instance for use in children. Less than 8 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 5 years of diagnosis. Among those children that 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 that 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

International Childhood Cancer Research

An analysis of the International Cancer Research Portfolio



What is included? The analysis includes all research awards relevant to cancer in children, adolescents and young adults in the ICRP portfolio from 2010 to 2015.



2485 childhood cancer projects

Projects funded by 68 organizations on 4 continents

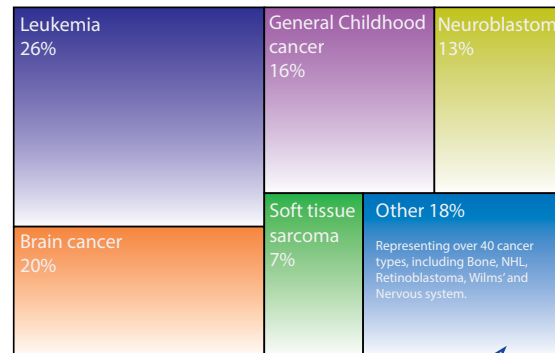
Total investment of over \$400m USD each year* on all relevant projects

66% wholly-focused on childhood cancer (4% of the overall portfolio)

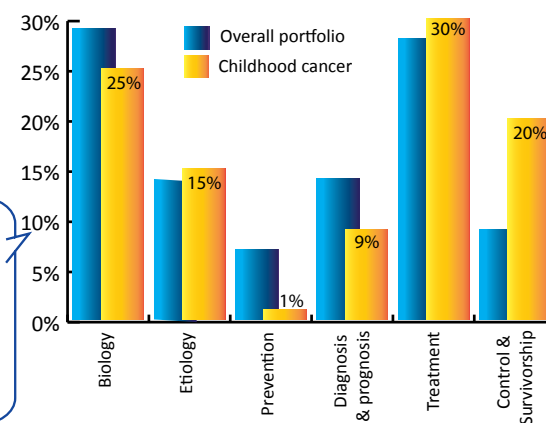
Over \$180m USD each year* on >1000 active projects wholly-focused on childhood cancer

*Average annual investment

The research profile for childhood cancer projects differs from the overall portfolio, with greater emphasis on Etiology, Treatment, Control & Survivorship



There is strong focus on research investment in cancers with a high incidence in childhood



Summary: ICRP organizations fund across the spectrum of childhood, adolescent and young adult cancers. While research investment in treatment, control & survivorship is strong, relative investment in prevention is low. This analysis gives a baseline to measure the impact of current and new initiatives to boost childhood cancer research and methodology has been developed to track future investment trends.

"Identifying Novel Therapeutic Combinations with 131I-MIBG to Treat Relapsed and Refractory Neuroblastoma"
San Francisco, US (2015-2017)

Over 160 awards for clinical trials and clinical infrastructure.
For example...

"Infusion of IL-15 activated NK cells after allogeneic stem cell transplantation in children with relapsed/refractory leukemia: a feasibility study"
Leiden, NL (2013-2016)

"Phase II trial of oral vinorelbine in children with progressive or recurrent unresectable low grade glioma"
Lille, FR (2012-2016)

"Intergroup trial for children or adolescents with B-cell NHL or B-AL: evaluation of rituximab efficacy in high risk patients"
Birmingham, UK (2012-2022)

"A multicentre phase II randomised controlled trial of a parent/carer-targeted intervention to improve quality of life in families of young cancer survivors"
Sydney, AU (2014-2017)

About ICRP

The International Cancer Research Partnership's mission is to add value to cancer research efforts internationally by fostering collaboration between cancer research funding organizations. To find out more, or participate in future analyses, visit our website <https://www.icrpartnership.org>





CAC2.org ■ info@cac2.org
Coalition Against Childhood Cancer ■ PO Box 41913 ■ Philadelphia PA 19101

