# 2017-2018 ANNUAL REPORT



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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## ABOUT US

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. 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.

### PRESIDENT'S MESSAGE

Members and Friends,

I'd like to welcome everyone who joined CAC2 this year. The list includes ten childhood cancer organizations, nine individuals, nine students, and three supporting organizations. 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 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. CAC2 has worked over the last year to serve, educate, connect, and engage our diverse community.

**Serve.** This year we completed our seventh of seven collaboration projects begun since our founding: a sweeping overhaul and re-launch of the Hope Portal, the most comprehensive curated database of non-profits providing assistance to childhood cancer patients and their families. This robust search tool, developed and supported by CAC2, KBI Biopharma, the Association of Pediatric Hematology/Oncology Nurses (APHON), and the Association of Pediatric Oncology Social Workers (APOSW) allows childhood cancer families across the country to find support faster, with less effort, and in a more personalized way than ever before.

**Educate.** Through our bimonthly 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. In addition, we launched a new initiative to collect and translate science articles important for our community and archive them in the CAC2 Curated Research Library. We also updated the off-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.

**Connect.** As in the past, we continued to serve as a conduit for information to our members and out to our various stakeholders. To help our members connect with and support one another directly, we launched an internal listserv this year. We also encouraged members to build on themes explored at the 2017 CAC2 Annual Summit in Chicago to promote and enable more joint work. In addition to our member-endorsed collaboration projects, in 2017-18 our members amplified their individual efforts through bilateral partnerships, pooled funding and pooled action efforts, and complementary targeted funding.

**Engage.** We also provided our members numerous opportunities to participate in community-wide social media campaigns. Our efforts yielded major legislative successes, including the passage of the RACE Act and STAR Act, and created a swell of interest in International Childhood Cancer Day in February. We continued 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 stand in awe of the initiative, energy, and imagination of our members. They exemplify everything that is unique and impactful about our community. Thank you for your partnership.

With everlasting appreciation, Vickie



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 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 cancommunity benefits from greater levels cer 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

Joy Cruse, CAC2 Meetings Co-Lead TeamConnor Childhood Cancer Foundation

Ginger Diamond, Secretary & CAC2 Meetings Co-Lead Tom Pilko, Nominating Chair Childhood Cancer Awareness Group of Coffee County Individual Member

Angie Giallourakis, Family Support Interest Group Liaison Tony Stoddard, Awareness Interest Group Liaison Steven G. AYA Cancer Research Fund Sophia's Fund

Jess Kean, Communication Lead & Advocacy Group Liaison Julie Sutherland, Marketing and Materials Lead Make Some Noise: Cure Kids Cancer Foundation Children's Cause for Cancer Advocacy

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

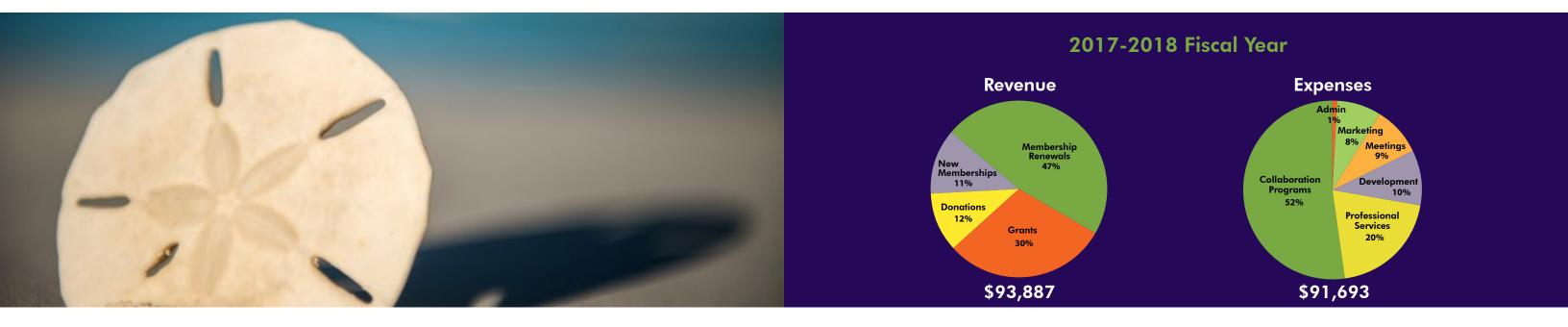
Donna Ludwinski, Professional Meetings/Speaker Liaison Solving Kids' Cancer

Kyle Matthews,	Technology	Lead
Beat Nb		

Steven L. Pessagno, Treasurer Individual Member

Lisa Towry, ICRP Project Lead Alex's Lemonade Stand Foundation





## TREASURER'S REPORT

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

In the President's Message in this Annual Report, Vickie summarizes how CAC2 continues to grow and positively impact the childhood cancer community and the patients, angels, survivors, and families we serve. Having delivered seven out of seven collaborative projects, CAC2 now looks ahead to design and deliver at least an eighth project in the coming year. We will do so while continuing to Serve, Educate, Connect, and Engage with our membership and the community on a daily basis.

The extent to which CAC2 can deliver an eighth and perhaps even a ninth project in the coming year will depend on our ability to at least maintain membership revenue (which grew by 20% this year) and expand grants and charitable contributions (number [#] up by 55% but amount [\$] down by 25%) in support of CAC2's mission. Grants and charitable contributions typically account for approximately 60% of CAC2 annual revenue, whereas this year these revenue sources will account for 40% of annual revenue.

Operating expenses for CAC2 are on track to be managed to a slightly favorable budget variance this fiscal year, which ends June 30, 2018. This is consistent with previous years and contributes to the CAC2 Sustainability Fund, which is held in a Money Market account for capacity expansion (new projects) as well as to maintain and operate ongoing collaboration assets or programming (such as the Hope Portal). The organization does not have any long-term financial liabilities.

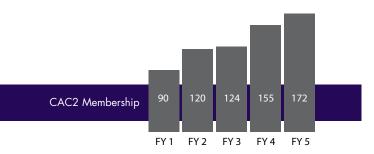
We expect operating expenses to increase notably in the coming Fiscal Year to bring onboard part-time, contracted Operations support; design and launch at least one new collaboration project; and implement "business as usual" support for the Hope Portal (for which CAC2 is responsible). This will necessitate some degree of revenue expansion for CAC2 as we forge ahead to make even greater impacts on the childhood cancer community, and especially for kids with cancer and their families.

CAC2 is eternally grateful for the volunteerism of its dedicated membership as well as the philanthropic support of our partners (corporations, non-profit organizations, and individuals alike). We rely on the donation of people's time, energy, and skills as well as their financial assistance to deliver on our mission. A perfect example from this year is the Hope Portal, the launch of which is made possible through countless hours over the years by our President, eight CAC2 members who will be honored as Volunteers of the Year, a notable amount of in-kind support and technical expertise from KBI Biopharma (a CAC2 Supporting Organization Member), and a generous grant from the Andrew McDonough B+ Foundation (a CAC2 Organization Member). This type of commitment and teamwork is exemplary, and a source of immense pride for CAC2.

We thank everyone who has believed in CAC2 throughout its first five years and has enabled our membership to achieve "seven for seven" in delivering projects in our foundational pillars of Awareness and Advocacy Support, Research and Treatment, and Family Support. We look forward to delivering more each year through powerful ideas, teamwork, and even greater levels of support.

Steven L. Pessagno Treasurer, Coalition Against Childhood Cancer







## SUPPORT

We make a bigger splash with your support!



sion. Such philanthropy drives CAC2's ability to invest in

new collaborative projects designed to generate positive

impact for kids with cancer and their families and allows

us to fund general operations to sustain CAC2 well into

Supporters of CAC2 make a difference for the 43 chil-

dren who are diagnosed every day with one of 12+ ma-

jor 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 pe-

diatric cancer survivors who experience lifelong, chronic

CAC2 extends heartfelt gratitude to the individuals, organizations, and companies who have provided charitable support to CAC2 in our 2017-18 fiscal year.

the future.

health-related issues.

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 cancer. 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 made an undeniable impact on the childhood cancer community, membership dues do not cover the organization's operating budget.

CAC2 relies on the generosity from corporations, nonprofit organizations, and individuals to advance its mis-

members.cac2.org/donate admin@CAC2.org CAC2 | P.O. Box 41913 Philadelphia, PA 19101



SUPPORT

volunteer support from

individual contributors.

### Sustaining Supporters (\$500+)

Erin's Dream Race GlaxoSmithKline Foundation Jaime L. Howard Laurie Orloski\* Northwestern Mutual of Dallas PPD Steven L. Pessagno\*

Sun East Charitable Foundation

### Support for the Hope Portal

Andrew McDonough B+ Foundation\* Amgen USA

AmazonSmile Foundation Amber L. Harper Andrea Needham Bookman and Florence Peters Diane B. and Dennis D. Schaefer Fatima Mirza Fran Andrews

\*denotes CAC2 member





## THANK YOU!

We love our supporters!

### 2018 Annual Summit Sponsors

Seattle Children's Hospital Juno Therapeutics, a Celgene company United Therapeutics Oncology Fred Hutchinson Cancer Center Northwest Indiana Cancer Kids Foundation\*

### Support for General Operations

Gail Schwartz Jan B. and John C. Taylor Jo Anne J. Bates Karen Ellis Woodruff Kathy Tillery-Kerr Laura Solomon & Associates Lauren Monks Laurie Lenox Lila Cashion Make Some Noise: Cure Kids Cancer Foundation\* Marsha and Murray Milford Mary McCafferty Mike Aquino Paul D. Lack Phyllis B. and William J. Lee Theodore V., Jr. and Joan C. Foote Vickie\* and Walter Buenger





## MEMBERSHIP

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 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

### CHILDHOOD CANCER **ORGANIZATION MEMBERS**

- A Kids' Brain Tumor Cure Foundation Addison Bryan Foundation Aiden's Army Alex's Lemonade Stand Foundation Along Comes Hope Andrew McDonough B+ Foundation
- aPODD Foundation Arms Wide Open Childhood Cancer Foundation ASK Childhood Cancer Foundation
- Be Strong, Fight On! Bear Necessities Pediatric Cancer Foundation

### Beat Nb

**Bike Bald** Books That Heal

Braden's Hope for Childhood Cancer Brooke's Blossoming Hope for Childhood Cancer Foundation Caleb's Crusade Against Childhood Cancer CancerFree Kids Candlelighters Childhood Cancer Foundation of the DC Metro Area Candlelighters of New York City Canines-N-Kids Foundation ccTHRIVE Childhood Cancer Awareness Group of Coffee County

Childhood Cancer Guides

Children's Cause for Cancer Advocacy Christing Renna Foundation

- CJ's Journey CURE Childhood Cancer
- Cure 4 the Kids Foundation

Cure4Cam Childhood Cancer Foundation

- CureSearch for Children's Cancer Designing Dreams
- **Dragon Master Foundation**
- **Elaine Roberts Foundation** Ellie's Hats
- Emily Whitehead Foundation for Childhood Cancer Research n Mawr PA End Kids Cancer San Luis Obispo, CA Evan's Victory Against Neuroblastoma Foundation Francesco Loccisano Memorial Foundation Gold in September Charitable Trust Gold Rush Cure Foundation
- Hugs for Brady Foundation I Care I Cure Childhood Cancer Foundation
- Jack's Angels Foundation Jeff Gordon Children's Foundation
- Jeremy Cares
- Joedance Film Festival
- Journey4ACure
- Julia's Grace Foundation
- Kids v Cancer
- Little Eric's Foundation
- MACC Fund (Midwest Athletes Against Childhood Cancer)
- Make Some Noise: Cure Kids Cancer Foundation Mattie Miracle Cancer Foundation Max Cure Foundation MIB (Make It Better) Agents Momcology Morgan Adams Foundation **Mystic Force Foundation** Nathan's Hope No More Kids with Cancer Noah's Bandage Project Northwest Indiana Cancer Kids Foundation **Open Hands Overflowing Hearts** Pediatric Brain Tumor Foundation Pediatric Cancer Foundation People Against Childhood Cancer Prayers for Elijah Precious Jules Childhood Cancer Foundation **Richi Childhood Cancer Foundation** Ryan's Case for Smiles Sammy's Superheroes SebastianStrong Foundation Solving Kids' Cancer Sophia's Fund Stand Firm Warrior Foundation Steven G AYA Cancer Research Fund Swifty Foundation TeamConnor Childhood Cancer Foundation Team G Foundation

Team Hailey Hugs Tennessee Cancer Consortium - Childhood Committee The Alexander Muñoz Memorial Fund The Get Well Gabby Foundation The Truth 365 This Star Won't Go Out Turn It Gold Carmel. N Wade's Army With Purpose Zoe4Life 3/32 Foundation Melissa Alderfer

The Grayson Saves Foundation The Ross K. MacNeill Foundation The Taylor Matthews Foundation The Truth 365 - Australia Ty Louis Campbell Foundation West Virginia Kids Cancer Crusaders **INDIVIDUAL MEMBERS** Greg Aune Joe Baber Vickie Buenger Bobbi Burke William Burns Wendy Carvotta Cathy Collins

Mary Beth Collins Casey Crossan Stephen Crowley Shane Dilling Joseph Dudash, Jr. Erin Ewald Karla Flook Judy Fulmer Kevin J. Kane Deborah Kochevar Ram Mohan Ram Kumar Angela Lee Maureen T. Lilly Robert Michael Madonna D. Lee Marchiano Noreen McGowan Hannah MacIntosh Marcia Miculek Brvan, TX Diane Moore Elise Morgan William Murray Hannah Neff Suzanne Nixon Laurie Orloski **Stephen Pecevich** Anthony Perrier Steven L. Pessagno



Joan Pilko Tom Pilko Barbara Polo **Brian Riggs** Neal Rourke Carleen Rufo-Miller Nicoletta Sacchi Sheri Sallee **Tim Schmeltz** al Falls MN Kelley Sharp Raquel Sitcheran Jeffrey Skolnik Susannah Koontz Webb Lori Wecht Robert Weker Wynnewood, P

### **STUDENT MEMBERS**

Matt Buff Saint Johns, F Catherine Chester MacKenzie Cruse Maddie Curtis

Paige DePagter

Rachel D'Eramo

**Christina Gonzales** 

Abrianne Joseph

Kelsey Leong

Nicole Lyons Kristin Mantlo Melinda Marchiano

Pallas Riedler

Caitlin Shannon

**Riley Stock** 

### SUPPORTING ORGANIZATIONS

Animal Cancer Foundation **Bristol-Myers Squibb** HealX ridae. England, Ut KBI Biopharma Loxo Oncology National Brain Tumor Society Novartis Oncology Rare Cancer Research Foundation Raleiah, NC



### JOIN US

Dive 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 grass-roots advocacy efforts
- •Discounted registrations at special programs
- •Participation in the CAC2 Project Incubator

### **MEMBERSHIP CATEGORIES**

**Childhood Cancer Organizations** 

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

### 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.



## IMPACT

Our 2017-18 initiatives and member-endorsed projects include our webinar series, the national launch of the next generation Hope Portal, significant legislative victories, and ongoing efforts to improve communication and coordination with families, researchers, and organizations. Recent successes within CAC2 and across the broader childhood cancer community make the celebration of our fifth birthday this year particularly sweet.

CAC2 focuses on how to create impact through collaboration. For too many years, childhood cancer has lacked adequate funding and faced multiple barriers to progress. Since our inception we have worked to build bridges, leverage individual strengths, and minimize duplication of effort among our members and within the larger community to combat those challenges. Our members have responded by finding novel and creative ways to combine their efforts and resources for increased impact.

In the area of research, childhood cancer organizations that work together have the potential to speed progress by shortening review cycles, reducing burdens for investigator applicants, and supporting increased scale for viable projects. In advocacy and awareness, more voices delivering a common message translate into more successes locally, nationally, and internationally. In family support, it means reaching more families and facilitating better matches between needs and services. At CAC2, we work every day to prepare the soil for increased collaboration.

Collaborative efforts can take many forms. As we look for ways to better amplify our collective voices or overcome funding shortfalls, we have identified and encouraged five types of collaborative initiatives currently emerging in our community: (continued on next page)







### IMPACT (CONTINUED)

- Pooled Funding aggregates the capital of two or more funders. A single organization may not have the means to fund a project fully. Sharing the funding commitment can ensure the implementation of important work.
- Targeted Co-Funding allows funders to deliberately but independently make grants to the same projects or programs.
- Leveraging Infrastructure provides a pathway for smaller or newer organizations to identify and fund projects without having to recreate in-house mechanisms to recruit, screen, and administer grant applications.
- **Pooled Action** gives organizations the chance to back the same initiative and coordinate while working towards a common goal.
- Collaboration Projects allow multiple organizations to work together to launch mutually agreed upon and mutually beneficial projects that none could do effectively alone.

Each of these approaches relies on different levels of shared effort and coordination, and over the past year, we have seen unprecedented progress and impact in our community through these various avenues. The biggest successes both within CAC2 and for the entire community resulted from these efforts. They include the passage of two major pieces of childhood cancer legislation and the launch of the Hope Portal. In each case, individuals and organizations put results over recognition, to pursue a shared goal to create a future without childhood cancers. The impact of these achievements will be felt for years to come.

The work we do together resonates across the community. We continue to look for ways to strengthen our structural foundation by adding new members, enhancing our technical capabilities, and improving the ways we communicate with one another, our partners, and the wider world. We work to impact representatives of the community in a wide variety of arenas - from forums to festivals to your local newspaper. We lift up the spirit of collaboration and shared action as often as we can: we have themed the 2018 CAC2 Annual Summit around IMPACT, so we can explore together how we can speed progress through education and collaboration.

### **EDUCATION**

- Webinars:
  - -The Role of IRB in Clinical Trials -Hope Portal -Germline Predisposition -Impact of Patient-Driven Philanthropy -CAC2 Spring Members' Webinar
- Annually Updated Childhood Cancer Fact Library
- Curated Research Library
- CAC2 Annual Summit



### **SUSTAINABILITY**

- Membership Growth
- Infrastructure Enhancements
- Leadership Recruitment ٠
- Communications Development



### COMMUNITY

- CureFest
- CAC2 Welcome Event
- RACE Act Passage
- STAR Act Passage
- CAC2 Annual Summit
- International Childhood Cancer Awareness Day
- Twitter Team







### COLLABORATIVE HIGHLIGHTS June 2017 - May 2018

### Celebrating the collaborative successes of our members and CAC2!



### **RACE Act: Lowering Barriers to Clinical Trials**

CAC2 members worked collaboratively with other advocates and legislative officials to write and ensure the passage of the RACE Act. Passed in 2017, the RACE Act is a long overdue law, which requires companies to open clinical trials for children with cancer when the agents they are developing for adult cancers have similar molecular targets.



### Hope Portal: Patient Support Tool

Working with our collaborative partners: APHON, APOSW, and KBI Biopharma, CAC2 has proudly re-vamped, expanded, and re-launched the Hope Portal as a comprehensive, curated, and searchable database of childhood cancer resources.



### STAR Act: Comprehensive Legislation

CAC2 members helped shape and advance the Childhood Cancer STAR Act, which passed Congress and became law in 2018. The STAR Act will expand research opportunities, improve efforts to identify and track diagnoses, and enhance quality of life for survivors.



### CureFest 2017: Community Engagement

CAC2 continues to be an active participant at CureFest held in Washington, DC each September. Our involvement includes promotion, hosting the annual CAC2 Reception, and manning a tent on the Mall. In addition to our tent, many CAC2 member organizations are also present at CureFest.



### Pooled Funding -

### **CheckPoint Inhibitors: Brain Tumors**

CAC2 member organizations, Solving Kids' Cancer, A Kids' Brain Tumor Cure, and the Ty Louis Campbell Foundation, teamed up to fund a Phase 1 clinical trial of checkpoint inhibitors in the treatment of children with brain tumors. This rapidly led to a global Phase 2 clinical trial in 2018 conducted by CAC2 supporting organization Bristol-Myers Squibb.

### Nanoparticles: Solid Tumors

CAC2 member organizations Solving Kids' Cancer, Make Some Noise: Cure Kids' Cancer Foundation, and Arms Wide Open Childhood Cancer Foundation pooled resources to fully fund the initial phase of novel nanomedicine development and testing by Dr. Garrett Brodeur at the Children's Hospital of Philadelphia (CHOP).

# arget pediatric AML

our

Pennies

research for pediatric AML.

### Leveraging Infrastructure: Young Investigator Award

CAC2 member organizations SebastianStrong Foundation and Alex's Lemonade Stand Foundation have teamed up to support research for pediatric cancer using ALSF's "Young Investigator Award" as the vehicle. SebastianStrong is providing funds which will be matched by ALSF to provide the award.

### Pooled Action: Four Pennies Project for DIPG

CAC2 member organizations Pediatric Brain Tumor Foundation, Dragon Master Foundation, and the Swifty Foundation joined forces along with another non-member organization to create a pooled action initiative called the Four Pennies Fund with proceeds supporting the DIPG Initiative.



### Targeted Co-Funding: 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





## HOge Portal

The Hope Portal serves the core of our CAC2 mission, which is to put children and families first in everything we do and support organizations active in the fight against childhood cancer. The updated, expanded, and relaunched Hope Portal database makes it possible for cancer families to find sources of support to help ease the many burdens and challenges of childhood cancer.

### The Hope Portal opens the door

to support services available to childhood cancer patients and their families. This free, user-friendly patient support tool gives caregivers and healthcare professionals access to a searchable database of over 400 non-profit organizations that provide information and assistance to the childhood cancer community. Whether families are looking for financial support, gifts, activities, or just someone to talk to, the Hope Portal is one-stop shopping to help meet families' needs.

### Newly updated in 2018,

this robust and growing database will allow childhood cancer families across the country to find support faster, with less effort, and in a more personalized way than ever before. The Hope Portal is continually updated and returns search results by diagnosis, geographic location, and support category, providing caregivers and healthcare professionals with an easy tool to navigate a wealth of resources according to their specific needs.

### We invite our community

to visit the Hope Portal, share it with families, promote it within their hospitals, and invite additional organizations to join the Hope Portal. The Hope Portal site includes step-by-step directions for organizations looking to add or refine a listing and instructions for embedding the Portal onto an external site.

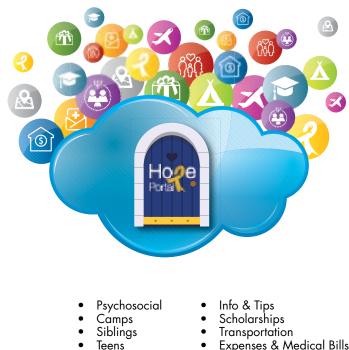
### Collaboration

is key to helping advance support opportunities and access for childhood cancer patients and their families. We are deeply grateful to the partnership that makes the Hope Portal possible.





### Your Gateway to Support Resources For Childhood Cancer Patients and Their Families



### hope-portal.org

Bereavement

Survivorship

- Expenses & Medical Bills
- Wishes & Gifts
- In-Person Support

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



### 2017 SUMMIT Ann & Robert H. Lurie Children's Hospital of Chicago







Phil Renna hristina Renna Foundation

Julie Sutherland Donna Ludwinski Make Some Noise: Cure Kids' Cancer

### **Research Conference Committee Leads**









Members and guests gathered at Lurie Children's Hospital in Chicago on June 28 and 29, 2017 for the CAC2 Annual Summit and Members' Meeting.

The Ann & Robert H. Lurie Children's Hospital of Chicago hosted CAC2's 4th Annual Summit and Members' Meeting. The two-day meeting featured rich programming, an abundance of networking opportunities, and action-oriented breakout sessions.

Our program highlighted many of the ongoing efforts in pediatric cancer to break down barriers that impede progress and to encourage new relationships and coordinated efforts to speed progress toward shared goals. We used our time together to forge new relationships, strengthen existing ties, and learn from one another in a robust and energized setting.

Investigators, clinicians, nurses, industry sponsors, and regulators joined members as we put the spotlight on the many ways we can work together to speed progress in our community. We offered the more than 100 attendees access to experts who presented on such varied topics as survivorship, the nurse-patient relationship, the importance and challenges of research funding in pediatric cancer, and the current state of DIPG research. We also devoted a full afternoon to exploring collaborative models for ensuring the advancement and acceleration of childhood cancer research.

This annual opportunity for our community to connect and share continues to open new doors for collaboration. Several meeting attendees have reported making connections with each other and developing partnerships that resulted in positive, and in some cases significant, outcomes. The potential of our community is unlimited when we work together.

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 ensure the success of the 2017 Annual Summit.





### 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.<sup>1</sup>
  - 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.<sup>2</sup>
  - 43 children per day, or15,780 children per year are expected to be diagnosed in with cancer.<sup>2</sup>
  - 1 in 285 children was diagnosed with cancer in 2014.<sup>2</sup>
  - Childhood cancer is not one disease there are more than 12 major types of pediatric cancers and over 100 subtypes.<sup>2</sup>
  - 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.<sup>3</sup>
  - On average, about 17% of children die within five years of diagnosis. Among those children that survive to five years from diagnosis, 18% will die within 30 years of diagnosis.<sup>4</sup>

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

### Every child deserves the chance to live a healthy life.



- There are 70 potential life years lost on average when a child dies of cancer compared to 15 potential life years lost for adults.<sup>5</sup>
- 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.<sup>6</sup>
- 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.<sup>7</sup>
- 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.<sup>8</sup>
- Symptoms of post traumatic stress disorder are well documented for parents whose children have completed cancer treatment.<sup>9</sup>
- 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.<sup>10</sup>





<sup>1</sup> 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

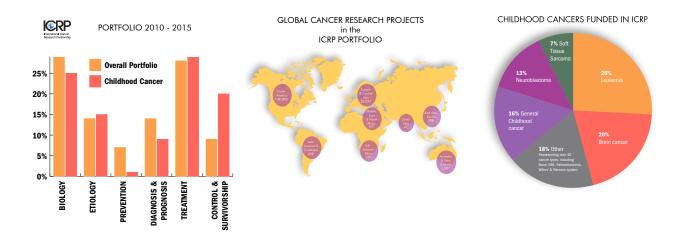
<sup>2</sup> American Cancer Society, Childhood and Adolescent Cancer Statistics, 2014 http://goo.gl/y5RXyv 3 National Cancer Institute, http://www.cancer.gov/research/areas/childhood 4 Journal of the National Cancer Institute "Cause-Specific Late Mortality Among 5 Year Survivors" http://jnci.oxfordjournals.org/content/100/19/1368.full 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 Cancer Care for the Uncer Care for the Cause 2013.



### Partnering for Lasting Impact

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 (ICRPartnership. 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-

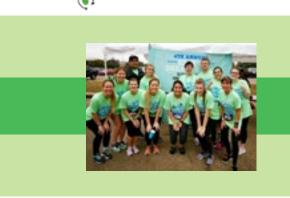
ing the ICRP, a unique code has been retrospectively applied to the over 80,000 projects in the database, indicating if it has a childhood cancer application to make searching for these projects easier. Data provided to the ICRP by CAC2 members contributed to a first-time analysis of the childhood cancer 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.





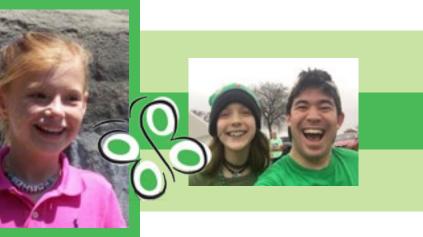
### Erin's Dream Race contributes annually to support the CAC2 mission.

Erin's Dream Race began as a grass roots event in 2014 at Texas A&M University (TAMU) in memory of Erin Buenger, daughter of CAC2 President, Vickie Buenger and her husband Walter, and who battled neuroblastoma for nearly seven years. The race organizer, Verity McInnis, a professor at TAMU, was deeply touched by Erin, and believes in the mission of CAC2 and its importance to the childhood cancer community. Erin's Dream Race is modeled in the collaborative spirit of CAC2, as Dr. McInnis and various student groups work together to make the 5k race a reality; TAMU Women's Soccer team members have served as safety marshals each year. In just 4 short years, Erin's Dream 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 in order 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.









Erin Buenger, Inspiration for Erin's Dream Race









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