

Annual Report

June 2014

Coalition Against Childhood Cancer (CAC2)



COALITION AGAINST
CHILDHOOD CANCER

Let's imagine our future together working for a world without childhood cancers.

June 25, 2014

Dear Coalition Against Childhood Cancer member,

I am pleased to present our membership with this document reporting on our first year of operations. It contains a report from the treasurer about our financial condition and items from our various standing committees and updates from our project leads.

I recently re-read this quote from Antoine de Saint-Exupéry, the French writer and aviator, who wrote *The Little Prince*.

“If you want to build a ship, don’t drum up people to collect wood and don’t assign them tasks and work but rather,
teach them to long for the endless immensity of the sea,”

From my observation, the key to collaboration isn't endless amounts of time and effort trying to foster collaboration through technology, training, and emails. **It's purpose.** Purpose is collaboration’s most unacknowledged determinant. It's what let all those engineers bring the crew of Apollo 13 home safely and what it took to get 5000 planes out of the sky and landed in various unscheduled airports after the 9/11 crashes. It is what keeps our members doing more to help children with cancer and their families every day. For all you have done, are doing, and will do, I thank you.

Vickie Buenger
President, CAC2

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1 CAC2 DEVELOPMENT COMMITTEE

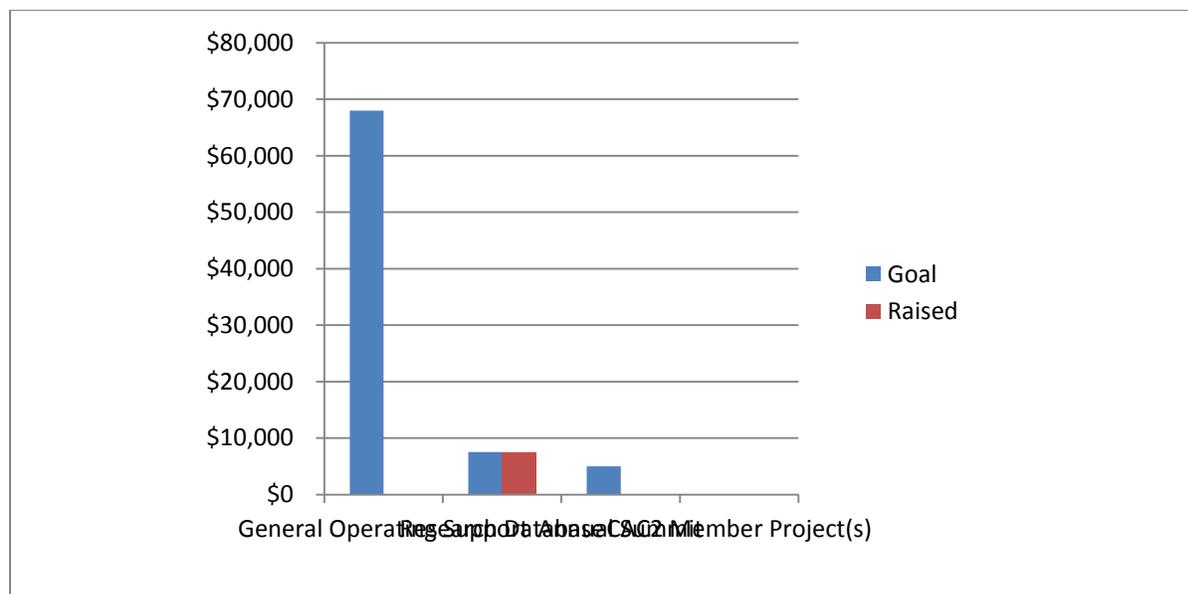
Committee Members

Vickie Buenger, CAC2 President and Cancer Advocate
Jaime L. Howard, CAC2 Development Consultant and Member
Robert Madonna, CAC2 Member and Cancer Advocate
Steve Pessagno, CAC2 Treasurer and Cancer Advocate
Tom Pilko, CAC2 Member and Cancer Advocate

Fundraising Activity

Beginning October 15, 2013, CAC2 began pro-actively seeking contributions from institutional (corporate, foundation, and agency) donors to provide seed funding, general operating support, and programmatic/project/event support. The focus has been on the FY 2015 budget with an aim to raise \$80,500. Below is a chart of activity to date.

FY 2015 Expense Budget/July 1, 2014-June 30, 2015:	\$105,000
FY 2015 Contributed Revenue Goal:	\$80,500
Contributed Revenue to-date:	\$7,500



Proposal Overview

Total # of Proposals Submitted:	11	Total Amount of Requests:	\$151,500
# of Proposals Funded:	1		
# of Proposals Declined:	8		
# of Proposals Pending:	2		

Successes and Challenges

The Committee has successfully established a dialogue with funders on behalf of CAC2 and is building awareness about the organization, our members, and CAC2 activities and projects. Corporations and foundations have expressed excitement about CAC2 and its work, shared a desire to learn more, and communicated a willingness to develop a relationship between our respective organizations.

The greatest challenge and one that has resulted in a barrier to acquiring charitable contributions is the fact that CAC2 has not independently established its 501(c)3 status to date. When the IRS determination is complete, the Committee anticipates increased proposal and funding activity. Of note, the one grant received to date for CAC2 was awarded to a member organization and allocated to a CAC2 project.

Additionally, CAC2's strategic decision to not pro-actively seek support from individuals or corporations/foundations that may conflict with member organizations' philanthropy programs creates a significant challenge by limiting proven fundraising methods for national membership organizations and decreasing the number of prospects that CAC2 may pursue.

Resources Needed for FY 2015

The Committee will continue to research, identify, and cultivate donor relationships on behalf of CAC2 with a primary goal to secure charitable support (financial contributions, as well as gift-in-kind donations and pro-bono services – when applicable) for the organization and member projects. In order to be most effective and successful, the Committee respectfully requests the following from CAC2 Board and Committees.

- 1) Additional Development Committee Members – The Committee meets monthly via phone and coordinates most activity in the interim via email. To accomplish CAC2's development goals, Members are asked to participate in strategic planning discussions, serve as ambassadors in their respective communities to build awareness on behalf of CAC2, identify and make introductions to (if appropriate) potential funders for the Development Consultant to pursue, and develop relationships with prospective funders (if Member feels comfortable doing so).
- 2) Committee Collaboration – As CAC2 Committees meet to discuss organizational communications and marketing strategies, events, or member projects, coordination with the Development Consultant is important to a successful development program for CAC2. The more information the Development Committee has regarding CAC2 activity, the more effective the Committee can be in identify and seeking donor opportunities to support CAC2 priorities and initiatives.
- 3) Approval to Pursue Individual Giving – The Development Committee may expand its purview and potentially increase impact with permission to develop fundraising strategies to engage individual donors with CAC2. For example, there is opportunity to develop a call to action for a specific project using a crowdfunding platform to raise visibility and generate charitable revenue. Additionally, we can passively or actively pursue funding through social media or email campaigns.

2 CAC2 MEMBERSHIP COMMITTEE

Committee Members

Beth-Ann Krimsky—I Care I Cure Childhood Cancer Foundation

Donna Ludwinski, --Solving Kids' Cancer

Pat Tallungan—Children's Neuroblastoma Cancer Foundation

Liz Scott—Alex's Lemonade Stand Foundation

Amy Weinstein—A Kids' Brain Tumor Cure Foundation

Amanda Bowen—Gold in September, I Back Jack

Marcia Miculek—Individual Advocate

Membership Committee Accomplishments

1. Gathered names, email addresses, contact information and prospect data for over 125 childhood cancer organizations or individuals connected to the childhood cancer community to create CAC2 Membership Prospect List
2. Created membership recruiting materials
3. Created membership renewal application and processes including related correspondence
4. Created welcome and thank you for joining membership correspondence
5. Assigned portions of Prospect Lists to committee members to pursue new member prospects and to raise awareness of CAC2
6. Achieved over 18 new memberships since October 2013
7. Continuing to pursue mission to have CAC2 include additional members so as to reach a larger audience for awareness purposes and collaboration opportunities including sharing of best practices
8. Set Record Date for members to vote as 30 days prior to the meeting (with the exception of the June 2014 meeting for which the Record Date is set at June 10, 2014)

Next Steps

1. Continue new member prospect cultivation
2. Continue renewal process
3. Serve as a resource and data collection point for members to introduce new potential members to CAC2
4. Set measurable goals for membership committee to achieve

Renewal Application and Process

1. Approximately two months prior to the expiration of any member's annual membership, we will send the member a renewal application.
2. The renewal application will already contain the member's information and ask only that the member update the information if necessary

3. Upon receipt of the completed renewal application and payment, the renewing member will receive an email thanking the renewing member for continuing to participate in CAC2
4. We anticipate renewal applications being issued on a monthly basis such that we will have rolling renewal throughout the year.
5. If the renewal is not received, membership committee follow up will take place as a reminder and/or an exit interview so we can attempt to learn why the renewal did not occur.

3 CAC2 MEETING COMMITTEE

Committee Members

Karla Flook—Individual Advocate
Joy Cruse—TeamConnor Childhood Cancer Foundation
Joe Baber—Individual Advocate
Gavin Kerr—ConKerr Cancer
Lance Thayer—Have Faith Be Strong
Lisa White—Rock Against Cancer (Gold Ribbon Project)
Lori Earl—This Star Won't Go Out
Bob Piniewski—PAC2

Special thank you to: Lori Earl for working on the hotel accommodations for the Annual Summit/Meeting; Joe Baber for printing the name tags and for printing the attendee packets and putting them together; Bob Piniewski for always lending an ear and answering questions.; and to Microsoft for hosting our meeting and providing so many resources to make our meeting great.

The Meetings Committee planned and organized the Face-to-Face Board Meeting, held in Dallas, TX on January 24, 2014.

Our largest task was to plan, organize, and conduct the 2014 CAC2 Annual Summit and Business Meeting. We made the decision to hold our meeting in conjunction with the Childhood Cancer Alliance's Awareness Days so that it would be easier for our members to attend both events if they wished. We also felt it would give us more visibility for prospective members who might be interested in attending. We want to thank Maureen Lilly for putting us in contact with Microsoft and facilitating that relationship. Microsoft agreed to provide us with a place to meet at "no charge."

A survey of the membership was conducted, asking members to rank in order "topics of interest." After the results of the survey, we started contacting and finalizing guest speakers. Speakers were: William Burns, the uncle of Josh Harding; Joan Darling, president of the COG PAC; Panel about barriers in drug development, moderated by Gavin Lindberg; Dr. Lee Helman, Dr. Malcolm Smith (NIH/NCI), David Arons (DCLG) & Dr. Jeffrey Skolnik, GlaxoSmithKline; Rachel Stauffer (DeGette-CO) and John Stone (Upton_MI) on 21st Century Cure Initiative. Andy Taylor (McCaul -TX) and Erika Appel (Van Hollen-MD) were also invited to speak about the Congressional Childhood Cancer Caucus.

We also want to thank Trish Kreiger and her team for posting our Save the Date information on the web site, for putting the meeting information in the newsletters and also creating and sending the Annual Summit/Meeting invitation and setting up the registration as well. Registration was open to Members only for the first two weeks and then opened up to anyone who wished to attend.

The Meetings Committee called and checked with several hotels in the area by Microsoft. We did arrange special rates with the Henley Park Hotel and the Washington Plaza Hotel. We

arranged for the special rates given to participants of the Childhood Cancer Awareness Days to be extended for those who wished to stay for the CAC2 meeting.

The Meetings Committee was responsible for finding a venue for our “Meet & Greet” reception, in a location close to Capitol Hill (to make attendance easy for those who had spent the day lobbying). After several phone calls, we were able to make arrangements with the 201 Bar to host the event. CAC2 provided heavy appetizers and a cash bar was available. We were also responsible for checking with the caterers on the “Microsoft Preferred list” to obtain breakfast and lunch for the Meeting/Summit. We also obtained a cake to celebrate CAC2s First Birthday!

We arranged to have a networking lunch around the 4 pillars (Advocacy, Awareness, Family Services, Research). We provided a meeting packet, which included the schedule, speaker biographies, committee reports, and an evaluation to assist in planning next year’s Annual Summit/Meeting.

4 CAC2 WEBSITE COMMITTEE

Co-Committee Chairs: Julie Sutherland & Kyle Matthews

2014 Goals

Our Committee assumed the task of maintaining, editing, and updating the CAC2 Website in January 2014. We worked with Communications to: 1) streamline the content of the website, 2) promote the CAC2 mission of collaboration, 3) provide increased value to members and 4) continue to provide information to the general public and families.



Stream Line: To clear out the text heavy and info-graphic-laden landing page, information was relocated to new pages in the “About Us” section of the website, and new tabs were created in a drop down menu for “About Us.” Additional streamlining will be evaluated as we learn how users are engaging with the site.

Provide Value Added Section for Members: To provide our members with value added options, we collaborated on the creation of monthly info session calls and a “members only” section of the website where members login to access call & meeting information, download forms/documents, engage with each other, and see current calls-to-action for tracks that interest them.

Promote the CAC2 Mission of Fostering Collaboration: To support and encourage collaboration we created the locations for *Collaborative Showcases* in each Members Section Pillar and will be creating a *Master Showcase of Collaborative* highlights on the public section of the website to highlight our members successful collaborations!

Collecting Information: To date, information regarding collaboration has not been uniform in its reporting, or its accessibility to the Website Committee. Therefore, in an effort to create a streamlined reporting method for our members, we created a “*Collaborative Success Report*” web-form for members to report their achievements and be showcased in a uniform and informative manner! [Link to Fillable Form](#)

Analytics: The CAC2 website receives about 600 visits/month, with 55% being new visitors. The average time per visit is 3.3 minutes, and visitors click an average of 3 pages. The top pages visited: Home Page, (544 visits), Members Listing, (121 visits), and Join, (104 visits)

2015 Goals: The Website Committee goals for the coming year include:

- Work with reps from each pillar/track and the Communications Committee to obtain content for Members only Pillar pages and update content for the public website
- Actively share the Collaborative Success Report
- Add the Childhood Cancer Event Map and the Research Data Base to the website, and finalize the Hope Portal
- Continue to provide information to the general public and families.
- Continue streamlining the website.
- Members are encouraged to help CAC2 promote its mission by participating in the following manners:
 - Visit the Members Portal on a regular basis to check for news & updates
 - Take advantage of the Pillar specific pages in the members portal to learn more about other members whose missions align with yours.
 - Submit Collaborative Success Reports for past collaboration between members so we can showcase your accomplishments and inspire others!

5 CAC2 HOPE PORTAL TEAM

Purpose

To create an online resource guide for childhood and adolescent/young adult cancer information that allows users to customize their search based on age, diagnosis, country/state, and 28 additional topics such as Advocacy & Awareness, Clinical Trials, Coping, Fertility, Financial Assistance, Nutrition, etc. Our goal is to collect essential resources in one place so that searching for information is easy and that the information provided is reliable.

To achieve this goal, CAC2 members and the staff of the HOPE Resource Center for Health Education at Children's Hospital Los Angeles (www.chla.org) are collaborating to add enhancements to the Hope Portal (www.searchhope.org). Over the last 18 months, weekly conference calls have been held and a strong partnership has evolved. We greatly appreciate the expertise offered and dedication shown by the following:

Kathy Ruccione, PhD, RN, FAAN, Director HOPE Resource Center for Health Education, CHLA. Kathy also co-authored *Childhood Cancer Survivors* and is the President-elect of the Association of Pediatric Hematology Oncology Nurses (APHON).

Susan Gantan, MPH, Health Education Services Coordinator, HOPE Program; HOPE Resource Center Coordinator, CHLA

Diane Moore, CAC2 and Striving for More

Jennifer Louis, CAC2 and TN Cancer Coalition/Childhood Committee

CAC2 Advisors: Vickie Buenger, Trish Kriger, Joe McDonough, Tom Pilko

In addition, many thanks go to these CAC2 members who have volunteered to review Hope Portal Application Forms once the enhanced site is launched:

Jennifer Gowen—Luck2Tuck Foundation

Nancy Keene—Childhood Cancer Guides

Catherine Lepone—Making Headway

Dawn & Bobby Norman—Hope for Tomorrow

Jennifer & Lance Thayer—Have Faith Be Strong

Jeremy Shatan—Hope & Heroes Children's Cancer Fund

Accomplishments & Progress:

1) Hope Portal enhancements include:

a) Adding: Country & State filters

b) Refining: 28 Topic filters (including 4 new Financial Assistance topics)

c) Expanding: Number of Resources

i) Resource Application (online form) & Cover Letter

ii) Application Review Process

iii) Linking Guidelines

2) Memorandum of Understanding agreed upon by CAC2 and CHLA

- a) CAC2 Acknowledgments
 - i) Hope Portal website
 - ii) Cover Letter
 - iii) Resource descriptions
 - iv) CAC2 members given priority during Application Review Process

Action Items:

- 1) Train Reviewers
- 2) Test Application/Review Processes
- 3) Redesign CAC2 Family Resources web pages
- 4) Launch enhanced Hope Portal
 - a) Present Hope Portal webinar to CAC2 membership
 - b) Promote Hope Portal to Resource database (500 organizations)
 - c) Contact Press/Media

CAC2 Volunteers Needed: Additional CAC2 Reviewers will be needed on an ongoing basis. Reviewers will vet all applications, in order to ensure that the site is providing accurate information. After reviewers are fully trained, we anticipate that each volunteer will review two applications per week, which should take no more than two hours per week. Please contact Diane Moore: diane.moore@mefinefoundation.org or Jennifer Louis: jlouis5678@aol.com to learn more about this opportunity. We hope you will join us in creating an extremely valuable tool for families and medical providers!

6 CAC2 ICRP TEAM

Background: Pre June 2013

- Research Database Committee formed to explore the options for sharing funded research in an organized and useful way. This committee explored creating our own CAC2 database as well as joining existing databases.
- The Committee recommended joining International Cancer Research Partnership (ICRP) because of the existing infrastructure, the various types of research and cancers represented that are able to be searched and the reasonable cost.

Since June 2013

- Applied for a grant from GSK to help support the cost of the first year's subscription to ICRP. The grant application was approved and CAC2 received the funds in the first quarter of 2014.
- Phone call with ICRP liaison, Lynne Davies, and CAC2, Steve Pessagno and Lisa Towry, to understand and draft an outline of steps for CAC2 members to upload their funded projects data into the ICRP.
- In order to search the ICRP, members must have contributed to the database by uploading their funded projects. Therefore, it would be best for CAC2 to have a process for uploading information before paying the ICRP membership fee.
- Outline of process (draft)
 - Use excel template (provided by ICRP) to organize data
 - Send to ICRP for them to apply Common Scientific Outline (CSO) coding, eventually CAC2 members will be responsible for coding their own data
 - Submit to ICRP for quality control testing and uploading
- Supplied a subset of data to ICRP to test the processes of coding large quantities of data
 - Used ALSF data from 2013
 - ICRP coded data and send back the analysis
- Set up a community call with Lynne Davies (ICRP) to outline the features of the database for CAC2 research focused members. Additionally, she will review in detail the coding technique behind the ICRP. The community call is scheduled for July 16, noon ET (invite has been sent by the communication committee).

Moving Forward

- Finalize the process for CAC2 members to supply, code and upload their funded projects (initially and yearly moving forward).
- Create a system to monitor which CAC2 members have participated (this is required for research focused members to be in good standing).
- Pay the ICRP membership fee; this is a yearly fee based on the size of CAC2. The recommendation by ICRP and the CAC2 committee is to have most of the infrastructure in place before we join because CAC2 will not be given access to the database until our projects are uploaded.
- Add a link to ICRP on CAC2.org (in a password protected section)

New Members for the Database Project Committee

- I have been serving as the lead and Steve as a consultant. I have one other CAC2 member who has volunteered and we welcome others!

7 CAC2 EVERGREEN MAP-CALENDAR TEAM

Introduction

At the CAC2 Inaugural meeting last summer, members reviewed and endorsed the Childhood Cancer Event Map project for highlighting September activities, programs, and events. The project team was formed and worked with many of you to create an on-line map showing the time, location and other information about childhood cancer events being held by members and non-members during September. The map was posted on CAC2 and shared by many members on their websites and social media. Map viewers (e.g., general public) were able to quickly identify childhood cancer events in their area, resulting in increased publicity and participation at your events! Here is a [link to the 2013 September Map](#).

The September project was completed, and after evaluation and voting by the CAC2 memberships, it was decided to make the Map evergreen, meaning it will include activities and events that occur throughout the year and will be updated, maintained, and distributed year round. This project will provide member organizations the opportunity to highlight activities in a way the general public and by media sources can access and share. The project team has identified several areas for improvement, including better graphics, simpler input, and better distribution.

The team expects to launch the map in September 2014.

Committee Members

Angie Giallourakis – The Steven G. AYA Cancer Research Fund
Bob Piniewski—PAC2
Jamie Collins—Neuroblastoma Consortium
Dawn Norman—Hope for Tomorrow
Jay Scott—Alex’s Lemonade Stand Foundation
Brian Riggs—Individual Advocate
Lance Thayer—Have Faith Be Strong

Map Committee Plan of Action

1. We need to finalize our Mission Statement to ensure the MAP project is in line with CAC2 goals and objectives.
2. A budget needs to be established based upon the software costs and management of the website (beyond volunteer staff). The budget request will also be submitted to grant writer, Jamie Howard.
3. Map Software Selection needs to be completed based upon specific criteria established by the Website Committee.
4. Lastly we will submit a report for the CAC2 Board to review and respond.

Any comments or questions can be directed to Angie Giallourakis:
angie@fightconquercure.com. Thank you!

8 CAC2 CUREFEST TEAM

CureFest Planning Committee Members

Bob Piniewski—PAC2
Tony Stoddard—Individual Advocate
Donna Carmical—Journey 4 a Cure
Laurie Orloski—Individual Advocate
Mikelle Raffel—Ryan’s Battle Buddies
Dena Sherwood—Arms Wide Open Childhood Cancer Foundation
Mike Gillette—The Truth 365

Current Plans

CureFest will be held on the National Mall on Sunday, September 21, 2014 from 9 a.m. until 1:30 p.m. To date, 93 childhood cancer foundations and groups have expressed interest in attending CureFest. (Last year 51 foundations and groups attended.) Over 1,000 individuals have indicated they will be attending, including over 300 volunteers.

This event is an excellent opportunity for the childhood cancer community and the general public to come together as one voice against childhood cancer. It is a family-friendly event with games and activities for all ages. The event will include speeches by prominent pediatric oncologists, elected leaders, as well as children and adults impacted by childhood cancer. There will be a master of ceremonies and live entertainment. There will also be moving tributes for children who have or have had cancer.

CureFest is held in the Nation’s Capital in an effort to make childhood cancer a national priority. There will also be a welcoming event the night before at Nationals’ Stadium. This is the home of the Washington Nationals baseball team. The facility is available because the team does not have a home game that day. Later in the evening, there will be a gold-themed candlelight rally near the White House.

Based on 2013 CureFest feedback, we made four significant enhancements in 2014.

1. Location Upgrade

We negotiated with the National Park Service and they agreed to allow us to host CureFest on the newly-renovated main Mall close to the U.S. Capitol. This is a much more prominent location and is very close to public transportation, food vendors and public restrooms.

2. CureFest Walk

For the first time, CureFest will include a 3-mile walk on the National Mall. Participants will enjoy historic views of the U.S. Capitol, the Washington Monument, The World War II Memorial, The Lincoln Memorial and The White House.

The CureFest Walk was added for several reasons.

One reason was to increase participation by the general public. Successful charity walks in the Washington-area typically start small but eventually attract several thousand participants within a few years of being established. There is a \$20 per person registration fee to help offset the costs of the event. Fees are waived for families directly impacted by childhood cancer.

A second reason is to provide foundations with a way to raise funds for their individual missions. When participants register for the Walk they will be have the option to raise funds for any childhood cancer foundation or group that endorses CureFest. Foundations do not have to attend the event but must be an established 501(c)3 charity in order to receive funds. Payments will be distributed to foundations through Crowdrise.

3. Professional Event Management

We have hired Jeff Ruday of Jeff Ruday Productions to manage CureFest logistics. Jeff is one of the country's leading event managers and has helped many small organizations expand their events from a few hundred participants to over 15,000 participants. The logistics of hosting an event on the National Mall are very complicated and Jeff's expertise will help ensure that the event runs smoothly.

4. Online Auction

Last year half of the 51 organizations that attended CureFest indicated that they could not afford to pay an event registration fee of any kind. This meant that two foundations (Journey4aCure and Arms Wide Open Childhood Cancer Foundation) had to use their funds to cover the bulk of CureFest's costs. These costs included permits, security and rentals of tents, tables, chairs, generators, portable toilets, a stage and more.

To pay for the operational expenses of CureFest we are hosting an online auction through 24 Auctions. Our goal is to raise approximately \$30,000 through the auction which opens on August 7. In order to reach this goal we will need the support of several childhood cancer foundations and advocates. Donations to the auction are being accepted at this time at <https://www.24fundraiser.com/curefest>

All proceeds from the auction and walk registration fee will be used to help offset the costs of CureFest. In the unlikely event there are any leftover funds, they will be rolled over into CureFest 2015. Currently Arms Wide Open Childhood Cancer Foundation is paying for the upfront costs of CureFest with the understanding that it will be reimbursed at the close of the auction. The goal of the event is to break even and no foundations will benefit financially from the auction or registration fees.

All foundations will have the opportunity to benefit from funds raised through the CureFest Walk and from donations received at the event on September 21, 2014

9 CAC2 FACT LIBRARY TEAM

Team Members

Joe Baber-The Nicholas Connor Institute
Richard Plotkin—Max Cure Foundation

The team continued expansion of the CAC2 Fact Library, and includes the following updated facts related to childhood cancer. The team will work with the Website Committee to ensure the latest facts are shown on the CAC2 website. Unless otherwise specified, all childhood cancer statistics below are for USA children younger than 20 years old (i.e. From zero to less than 20)

Diagnosis

- Childhood Cancer is on the increase ⁽¹⁾
- 1 in 285 children are diagnosed with cancer ⁽¹⁾
- 43 children per day or 15,780 children per year are diagnosed with cancer (10,450 ages 0 to 14, and 5,330 ages 15 to 20) ⁽¹⁾
- Average age at diagnosis is 6 years old, while adults' average age is 66 ⁽¹⁾

Survival

- 83% is the average 5 year survival rate for the Childhood Cancer category.^(1,3)
- Cancer survival rates vary depending upon the type of cancer. Survival rates can range from as little as 0% for cancers such as DIPG brain cancer or as much as 90% for ALL leukemia. ⁽¹⁾
- The survival rate without ALL leukemia factored in is 80%. ⁽¹⁾
- In 2010 there were 379,112 childhood cancer survivors. ⁽¹⁾
- Approximately 1 in 530 young adults between the ages of 20 years and 39 years is a survivor of childhood cancer. ⁽¹⁾

Long Term Side Effects Associated with Survival

- Approximately 98%⁽²⁾ of childhood cancer survivors will suffer late, side effect health issues associated with treatment for their cancers. Such late side effects as heart transplant, cardiac arrest, kidney transplant, and cognitive deficit disorders are just a few of the many serious health problems. Less serious, but moderate chronic health problems include infertility, asthma, immune deficiency disorders, vision problems, memory issues, fatigue, hearing loss, and depression.
- A recent St. Jude's study⁽²⁾ revealed that by age 50, childhood cancer survivors were likely to experience the following long-term effects:

Hearing Loss	86.5%
Heart Valve Disorders	83.5%
Pulmonary Dysfunction	81.3%
Pituitary Dysfunction	76.8%
Breast Cancer	40.9%
Primary Ovarian Failure	31.9%
Leydig Cell Failure	31.1%
Cardiomyopathy	21.6%

Mortality

- Cancer mortality for both children and adolescents declined from 2000 to 2010, with significant declines observed for multiple cancer types.⁽³⁾ However, unless more effective treatments are developed for childhood cancer, improvements in cancer mortality may have plateaued.⁽³⁾
- 1,960 children will die from childhood cancer⁽¹⁾ NOTE: Although this number is cited by both the ACS and the National Vital Statistics Report, it does not match the 83% overall survival rate cited above. We are doubtful of the collection method used to obtain this statistic therefore more investigation will be required.
- There are 71 life years lost when a child dies of cancer compared to 17 for adults.⁽¹⁾
- Mortality rate for cancer in hospitals is 10X the average for other causes of death in children⁽³⁾
- Cancer is the number one cause of death by disease.⁽⁴⁾
- Cancer is responsible for more deaths in children than all other diseases combined.⁽⁴⁾

Treatment, Research, Funding

- In the past 34 years, only two drugs, both used in the treatment of ALL, Teniposide (1980) and Clofarabine (2004), have been approved specifically for use in children. Since then, only four more new drugs, have been approved and they are used for both adults and children.⁽⁶⁾
- The Cancer Oncology Group (COG), through its budget from NCI, funds virtually all clinical trials for children while 60% of clinical trials for adults are paid for by private industry.⁽⁶⁾
- The average cost of a stay in a hospital for a cancer child is \$40,000 per stay.⁽⁵⁾
- In 2009, hospital costs associated with childhood cancer were \$859.8 million. It is now estimated to exceed one billion dollars.⁽⁵⁾
- For 2014, the National Cancer Institute (NCI) budget is \$5.06 billion while childhood cancer is only budgeted to receive \$208 million, or 4% of the total NCI budget.

¹ American Cancer Society, Childhood and Adolescent Cancer Statistics, 2014

² St. Jude's, (JAMA. 2013;309[22]: 2371-2381)

³ American Cancer Society, Declining Childhood and Adolescent Cancer Mortality, Cancer 2014

⁴ National Vital Statistics Report, vol. 62.6, December 20, 2013

⁵ Healthcare Cost and Utilization Project (HCUP), Statistical Brief #132, Pediatric Cancer Hospitalizations 2009

⁶ Peter Adamson, The Children's Oncology Group

Pediatric Cancer 5-Year Observed Survival Rates for 2 Time Periods, Ages Birth to 19 Years (1)

	YEAR OF DIAGNOSIS	
	1975-1979, %	2003-2009,* %
All ICCC sites	63%	83%
Leukemia	48%	84%
Acute lymphocytic leukemia	57%	90%
Acute myeloid leukemia	21%	64%
Lymphomas and reticuloendothelial neoplasms	72%	91%
Hodgkin lymphoma	87%	97%
Non-Hodgkin lymphoma	47%	85%
Brain and CNS	59%	75%
Ependymoma	37%	81%
Astrocytoma	69%	85%
Medulloblastoma	47%	70%
Neuroblastoma and ganglioneuroblastoma	54%	79%
Retinoblastoma	92%	99%
Wilms tumor	75%	90%
Hepatic tumors	25%	74%
Bone tumors	49%	73%
Osteosarcoma	45%	71%
Ewing sarcoma	42%	72%
Rhabdomyosarcoma	49%	64%
Testicular germ cell tumors	74%	96%
Ovarian germ cell tumors	75%	94%
Thyroid carcinoma	99%	98%
Melanoma	83%	95%

CNS indicates central nervous system; ICCC, International Classification of Childhood Cancers.

*Cases were followed through 2010.

Note: Does not include benign and borderline brain tumors.

Source: National Cancer Institute Surveillance, Epidemiology, and End Results (SEER) program, 9 SEER registries.

10 CAC2 ADVOCACY TEAM

Advocacy is one of the CAC2 organizing pillars.

This year, CAC2 members interested in advocacy have organized bi-monthly calls. The mission of the advocacy calls is to provide a forum for the free exchange of information to the childhood cancer community about legislative and regulatory initiatives that are being pursued by various organizations and provide opportunities for others to support those initiatives. Notes from the calls are posted on the CAC2 website.

To manage the bi-monthly calls, the Advocacy Coordinating Council was formed to organize and advertise the calls and to serve as moderators and note takers. The first Council volunteers include:

Jonathan Agin, Beth Anne Baber, Joe Baber, Vickie Buenger, Angie Giallourakis, Mike Gillette, Nancy Goodman, Maureen Lilly, Gavin Lindberg, Richard Plotkin, Tony Stoddard.

Many CAC2 members have participated in advocacy activities this year, most notably:

- #SaveJosh in March 2014
- Presentations in February 2014 to a National Cancer Institute panel on barriers to drug development for childhood cancer.

In addition to creating the series of advocacy calls this year, CAC2 made the following strides on the advocacy front:

1. Organized the May webinar with Dr. Peter Adamson, chair of the Children's Oncology Group, and Danielle Leach, co-chair of the Alliance for Childhood Cancer. The main theme was on the federal funding challenge for current childhood cancer clinical trials and no studies to take advantage of precision medicine.
2. CAC2 leaders are participating in an ongoing collaboration with leaders from the Alliance for Childhood Cancer and COG on federal funding. This collaboration reflects a growing spirit of cooperation among organizations to achieve a mutual goal, in this case, support for childhood cancer studies.

A "roadmap" of activities to increase awareness on the federal funding challenge for children with cancer is serving as a guideline for action. CAC2 members were strongly represented among the 250 advocates on Capitol Hill on June 24 as part of the Childhood Cancer Action Day. The #StepUp social media campaign was a 7-day virtual complement to the Hill meetings. The next steps in implementing increased awareness through 2014 include targeting a wider audience through social media, expanding our reach with Congressional representatives, and transparency with NCI.

11 CAC2 BUDGET & FINANCE COMMITTEE

Note from President: On behalf of all of CAC2 and the childhood cancer community we'd like to acknowledge and give a round of applause to Steve Pessagno for his untiring efforts to help children with cancer over the past four years.

- Financial Overview of CAC2 Fiscal Year 1: Expenses were lower than expected due to not hiring personnel (admin or managing director) as well as website work that was planned but did not get completed
- CAC2 currently has \$47K in its account
- Majority of funds came from membership dues with some seed funding
- CAC2 has received \$50K in grants to date. IMPORTANT TO NOTE: 70% of these came in the form of 1-time Seed grants. Development is going to be VERY important for CAC2 going forward
- Membership dues was at its highest in August 2013 with some coming in each month since
- CAC2 has paid out \$33K in expenses
- Fiscal Year 2 starts July 1, 2014 and has an expected budget of \$40,000 which could be comprised of \$30,000 from dues (if all members renew) and \$10,000 in new revenue