

Annual Report June 2015

Coalition Against Childhood Cancer (CAC2)



COALITION AGAINST
CHILDHOOD CANCER

June 17, 2015

Dear Coalition Against Childhood Cancer Member,

I am pleased to present you with this document reporting on our second year of operations (July 2014-June 2015). It contains a report from the Treasurer, Steve Pessagno, about our financial condition as well as items from our various standing committees and updates from our project leads. I have highlighted our last year's initiatives and activities for you below, and encourage you to read this document carefully to learn more about what we have all been up to!

I also would like to call your attention to this quote by American automaker, Henry Ford:

Coming together is a beginning, staying together is progress, and working together is success.

As the membership and financial reports show, we have continued to grow at a robust rate. But coming together is only the beginning. Staying together and working together is much more vital. We have made a great start, as evidenced by the many things we have initiated and worked on, but we cannot rest now. For all you have done, are doing, and will do, I thank you.

Vickie Buenger
President, CAC2

Highlights--CAC2 2014 Initiatives and Activity

Hope Portal--Coordinated with Children's Hospital of Los Angeles to build a comprehensive, searchable database of organizations providing family support and resources.

Childhood Cancer Fact Library--Developed an accurate and citable repository of childhood cancer facts, figures, and issues.

ICRP Database--Coordinated a central database of research initially funded by CAC2 members. 2014 year-end data reported by members was uploaded and will be accessible by mid-year 2015.

Evergreen Map-Calendar—Established a comprehensive online tool listing childhood cancer awareness and fundraising events.

Annual CAC2 Summit--Hosted its second annual CAC2 Summit bringing together members, partners, and special speakers on June 25, 2014, in Washington, D.C.

Childhood Cancer Caucus--Joined other groups in Washington, DC to promote the importance of advocacy, education, and awareness of childhood cancer. To that end, CAC2 co-hosted a luncheon honoring Congressional Childhood Cancer Caucus on September 19, 2014. Prior to the luncheon, CAC2

participated in the 2014 Childhood Cancer Summit, with Dr. Francis Collins, Director of the National Institutes of Health, as the keynote speaker.

CureFest in Washington, DC--Participated in and built awareness for CureFest, a festival and organized walk on September 21, 2014 in Washington, D.C. for the childhood cancer community and the general public to stand together against childhood cancer.

Gold Awareness Project--Offered CAC2 members creative ways to promote gold throughout the country and increase awareness of childhood cancer for the month of September 2014.

#StepUp Social Media Campaign--Collaborating with childhood cancer coalitions and organizations, CAC2 helped lead a coordinated community response plan in September 2014 to increase federal funding for childhood cancer research. The social media campaign, #StepUp, included targeted messaging to Congress, the NCI, and the general public, including op-eds and letters to the editor.

National Cancer Institute--Increased interchange between NCI and the childhood cancer community.

- CAC2 President Vickie Buenger was an invited speaker for the 2014 NCI-DCLG meeting on pediatric cancer.
- CAC2 member, Jonathan Agin, met with NCI Director Harold Varmus along with two other childhood cancer advocates in December 2014 to continue an open dialogue about issues impacting the pediatric cancer community.
- CAC2 members Donna Ludwinski, Solving Kids' Cancer, and Susan Weiner, Children's Cause of Childhood Cancer, served as invited panelists for the February 4-5, 2015 NCI-hosted Childhood Cancer Scientific Genomics Workshop.

Childhood Cancer Roundtable--CAC2 and its members engaged in the Childhood Cancer Policy Roundtable and actively participated in meetings, which began in September 2014. The Roundtable is pursuing legislative and administrative action in three areas: (1) "Maximizing Discovery through Research;" (2) "Accelerating Development and Availability of Promising Treatments;" and, (3) "Maximizing Delivery: Care, Quality of Life, Survivorship, and Caregiver Support."

CAC2 Ongoing Mission-Aligned Initiatives

- Semi-annual network meetings for information exchange, learning, collaborative project updates, and capacity building
- Comprehensive website for promoting members' collaborative successes and key initiatives
- Monthly webinar series discussing pertinent topics that include awareness, research, family services, advocacy, and general interest
- Member-driven Interest Group Forums to share timely information about common interests, issues, and opportunities and facilitate coordinated actions across the network – Interest Groups for Advocacy, Research, and Family Support are in various stages of organization

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1 TREASURER’S REPORT ON BUDGET & DEVELOPMENT

Lead: Steve Pessagno, Individual Member and CAC2 Treasurer

Development Committee: Steve Pessagno (Lead); Vickie Buenger (Individual Member and CAC2 President); Tom Pilko (Individual Member and Board of Directors member); Jaime Howard (contracted)

Executive Summary

As Coalition Against Childhood Cancer (CAC2) enters its 3rd Fiscal Year (FY3), which starts on July 1, 2015, the organization finds itself in stable financial condition for three primary reasons:

1. The Board of Directors and the membership continue to be exceptionally creative and thrifty on delivering on the organization’s mission – both through obtaining pro bono assistance (e.g., donated space for the annual meetings) as well as, most notably, through the high level of volunteerism inherent in CAC2 ways of working (i.e., the amount of hours that Board of Directors and Committee/Project leads and team members “donate” to manage the organization and implement its collaborative projects).
2. CAC2 realized a high renewal rate of memberships from Fiscal Year 1 to Fiscal Year 2 –84%. Please refer to Table 1.
3. CAC2 received higher-than-expected unsolicited grants/donations for the CAC2 operating budget, and the organization’s targeted Development efforts have resulted in several earmarked grants as well.

TABLE 1
CAC2 RENEWAL SUMMARY FROM FY1 TO FY2

Renewal Received YES	Renewal INDIVIDUAL	Renewal ORGANIZATION	Renewal STUDENT	Renewal Received NO	Renewal DECLINED	Removed - Lapsed
74	14	57	3	14	5	1
84%	78%	88%	75%	16%	6%	1%
of 100% total	of Individuals	of Organizations	of Students	Of 100% total	of 100% total	of 100% total

As of this writing (May 31, 2015), CAC2 has \$78,215.44 in tangible assets in the form of cash available in its bank account. This report provides a financial history and additional information for the financial state of CAC2 as it exists today.

Financial History

PRE-FISCAL YEAR 1: JAN 1, 2013 – JUN 30, 2013

Although CAC2’s 1st Fiscal Year (FY1) started on July 1, 2013, much work was required to set up the organization prior to the start of FY1. The individuals – then referred to the Council of Moderators – who devoted their own time to implement the launch of the organization completed a notable amount of that work without incurring expenses; however, the start-up work did require expenditure – mainly in the form of legal fees for drafting the Articles of Incorporation and documents required to register CAC2 with the US Internal Revenue Service (IRS). In order to fund these expenses, the Council of Moderators employed a strategy to obtain seed funding for the set up and launch of CAC2 (\$37,000.00). As CAC2 held its 1st Annual Meeting in June 2013 where Founding Member memberships were accepted, the organization realized membership dues in June 2013 ahead of the start of FY1 (\$1,050.00). During this period prior to the start of FY1, CAC2 operating expenses totaled \$8,839.20.

FISCAL YEAR 1 (FY1): JUL 1, 2013 – JUN 30, 2014

CAC2 started its 1st Fiscal Year with \$29,210.80 in its account, which was managed by the fiscal agent Philadelphia Foundation while CAC2’s 501c3 application was under review by the IRS.

During FY1, CAC2 took in \$31,500.00 in membership dues; \$4,550.00 of this amount was for renewals received in June 2014 going into FY2. CAC2 operating expenses for FY1 were \$29,616.65 – approximately the same amount deposited from membership dues. The Board of Directors approved a Development Strategy in FY1 whereby CAC2 pursued grant requests to help fund CAC2 operating expenses, either in general or earmarked for specific purposes. The agreed strategy – which remains in place currently – focuses on sources that do not provide program funding directly to childhood cancer patients and their families. To be sure, a key guiding principle for the CAC2 Development Strategy is obtain operating-expense funding from donor sources in a way that avoids entirely, or as much as possible, donor sources for CAC2’s member organizations.

CAC2 received 14 grants in FY1 totaling \$14,694.99. With the exception of a successful \$7,500 grant request from GlaxoSmithKline earmarked for an annual subscription to the International Cancer Research Partnership (ICRP) research database, the FY1 donations were made to CAC2 unsolicited.

CAC2 ended FY1 with \$44,739.14 in its account.

FISCAL YEAR 2 (FY2): JUL 2014 – JUN 2015

CAC2 operating expenses for FY2 are expected to come in approximately \$10,000 less than those for FY1, the key difference being approximately that amount in start-up legal expenses incurred in FY1. As of May 31, 2015, operating expenses has totaled \$17,662.30. Revenue from new membership and renewal dues have totaled \$24,700 to date for FY2 – a little over 80% of FY1 revenue for this category, indicative of the high renewal rate for memberships. Donations and grants currently stand at \$26,188.60 for FY2 – almost double the donations/grants from FY1. Notable donations/grants for FY2 include: approximately \$10,000 raised through Erin’s Dream Race (unsolicited and organized by Verity McInnis, PhD, in memory of CAC2 President’s daughter, Erin); a successful \$8,000 grant request from Bristol-Myers Squibb Company earmarked for the ICRP research database; and a \$5,000 unsolicited grant from McKesson Foundation in recognition of CAC2 individual member Diane Moore’s exceptional volunteer service in support of CAC2 and the Hope Portal project.

As of May 31, 2015, CAC2 has \$78,215.44 in its account.

Approach to Budget Management and Development Strategy

CAC2 will continue to seek grants to help fund its annual operating expenses, primarily seeking grants earmarked to specific budget items or collaborative projects. As CAC2 is almost entirely dependent on the time donated by the Board of Directors to lead the organization and on time donated by the membership to implement collaborative projects and run CAC2’s various Committees, the Board of Directors does believe that CAC2 will need to hire some amount of human resource in FY3 – either to help project-manage certain initiatives and/or provide the Board with administrative support. This type of operating expense has been envisioned since the inception of CAC2; however, the expense has not yet been incurred as it could be a relatively high operating expense – one that CAC2 is now in a position to incur to a manageable extent given the size of the membership and the amount of collaborative initiatives underway.

Additional Information

The remainder of this Financial Update provides specifics in the form of data tables and figures on the financial history and current budget status of CAC2. Please contact CAC2 Treasurer Steven L. Pessagno at admin@cac2.org with any questions.

TABLE 2
REVENUE: DONATIONS AND GRANTS RECEIVED

DONOR	Seed Grant (Pre FY1)	FY1 Jul 2013 – Jun 2014	FY2 Jul 20134 – Jun 2015
GlaxoSmithKline (via Alex's Lemonade Stand Foundation)	\$20000		
Alex's Lemonade Stand Foundation	\$10000		
Andrew McDonough B+ Foundation	\$5000		
Steven G. AYA Cancer Research	\$1000		
I Care I Cure Childhood Cancer Foundation	\$1000		
Liz and Jay Scott		\$100	
Bob Madonna		\$25	
Tom Pilko		\$25	
Beth-Ann Krimsky		\$25	
Alex's Lemonade Stand Foundation (for ICRP Research Database)		\$5000	
Victoria & Walter Buenger		\$500	
Steven L. Pessagno (for Website domain & email account)		\$120	
GlaxoSmithKline (for ICRP research database)		\$7500	
Maureen Lilly		\$25	
Steven L. Pessagno		\$100	
Joy Cruse		\$100	
Beth-Ann Krimsky		\$75	
Trish Kriger		\$100	
Karen Ciotti		\$1000	
Laura Solomon Associates			\$100
Sun East Charitable Foundation			\$500
Rebecca Hancock			\$1000
Ted Paup			\$100
Joanne Bates			\$100
Kenneth A & Peggy J Telg			\$100
Jonathan Coopersmith			\$50
Darla H. Menking			\$53
Jamberry Nails			\$11
M. Bookman Peters			\$250
Lila Cashion			\$50
Texas Presbyterian Foundation			\$1000
Verity McInnis			\$50
Erin's Dream Race			\$9800
Lisa Y. Ramos			\$25
McKesson Foundation			\$5000
Bristol-Myers Squibb Foundation			\$8000
TOTALS	\$37000	\$14695	\$26189

TABLE 3
REVENUE: MEMBERSHIP DUES

CATEGORY	Pre FY1 Jun 2013	FY1 Jul 2013 – Jun 2014	FY2 Jul 20134 – Jun 2015
New Membership Dues	\$1050	\$25900	\$4500
Renewal Dues	\$0	\$4550	\$20450
TOTALS	\$1050	\$30450	\$24950

TABLE 4
OPERATING EXPENSES

BUDGET ITEM	Pre FY1	FY1	FY2*
	Jan 2013 - Jun 2013	Jul 2013 – Jun 2014	Jul 20134 – May 2015
Managing Director	\$0.00	\$0.00	\$0.00
Administrative Assistant	\$0.00	\$0.00	\$0.00
Workers' Compensation	\$0.00	\$0.00	\$0.00
T&E	\$0.00	\$0.00	\$0.00
Meetings	3,339.20	\$6759.16	\$0.00
Membership Recruitment & Retention	\$0.00	\$0.00	\$0.00
Phone/Internet/Email	\$0.00	\$119.99	\$234.67
Web site development	\$500.00	\$1500.00	\$4550.00
Web site maintenance	\$0.00	\$970.00	\$1440.00
Project expenses**	\$0.00	\$0.00	\$1520.00
Legal	\$5000.00	\$12022.92	\$1081.51
Financial Services	\$0.00	\$1408.58	\$4179.24
Insurance	\$0.00	\$1111.00	\$1145.00
Postage	\$0.00	\$0.00	\$0.00
Communications	\$0.00	\$0.00	\$317.88
Development	\$0.00	\$5725.00	\$3195.00
TOTALS	\$8839.20	\$29616.65	\$17662.30
*FY2 has 1 additional month of expenses to come **1 st invoice for the ICRP database is due July 2015			

TABLE 5
HISTORICAL FINANCIAL SUMMARY

		FISCAL YEAR 1	FISCAL YEAR 2	BALANCE
	1/1/13-6/30/13	7/1/13-6/30/14	7/1/13-6/30/14	
Deposits - Grants	\$ 37,000.00	\$ 14,694.99	\$ 26,188.60	\$ 77,883.59
Deposits - Memberships	\$ 1,050.00	\$ 25,900.00	\$ 4,500.00	\$ 31,450.00
Deposits - Renewals	\$ -	\$ 4,550.00	\$ 20,450.00	\$ 25,000.00
Operating Expenses	\$ (8,839.20)	\$ (29,616.65)	\$ (17,662.30)	\$ (56,118.15)
BALANCE	\$ 29,210.80	\$ 15,528.34	\$ 33,476.30	\$ 78,215.44

FIGURE 1A
CAC2 GRANTS: COUNTS

COUNTS									
TOTAL	Seed	Individual-Member-General	Individual-NonMember-General	Individual-Member-Earmarked	Individual-NonMember-Earmarked	Org-Member-General	Org-NonMember-General	Org-Member-Earmarked	Org-NonMember-Earmarked
37	5	10	13	1	0	0	5	1	2
100%	14%	27%	35%	3%	0%	0%	14%	3%	5%

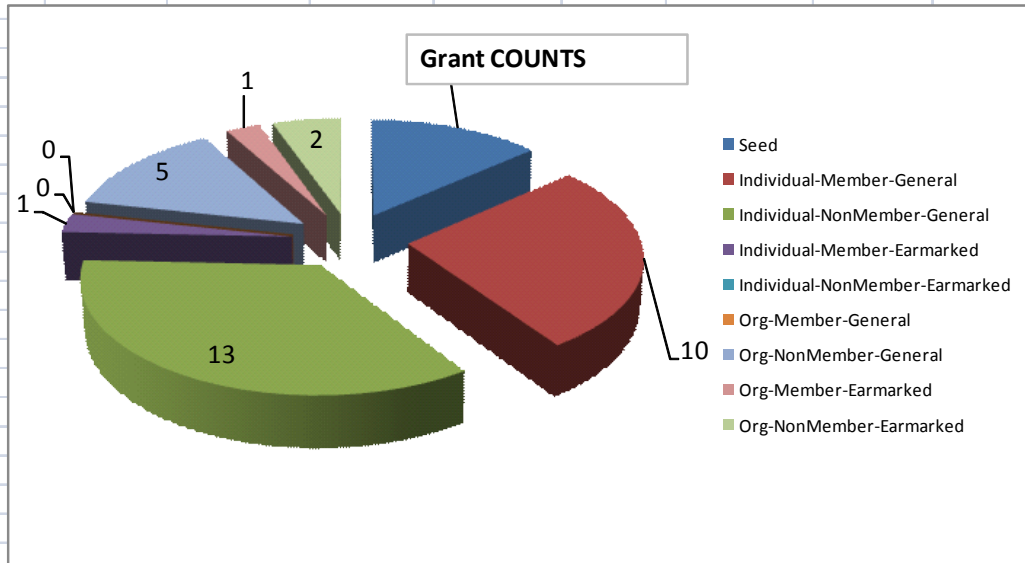


FIGURE 1B
CAC2 GRANTS: AMOUNTS BY CATEGORY

AMOUNTS									
TOTAL	Seed	Individual-Member-General	Individual-NonMember-General	Individual-Member-Earmarked	Individual-NonMember-Earmarked	Org-Member-General	Org-NonMember-General	Org-Member-Earmarked	Org-NonMember-Earmarked
\$ 77,883.59	\$ 37,000.00	\$ 1,075.00	\$ 3,678.00	\$ 119.99	\$ -	\$ -	\$ 15,510.60	\$ 5,000.00	\$ 15,500.00
100%	47.5%	1.4%	4.7%	0.2%	0.0%	0.0%	19.9%	6.4%	19.9%

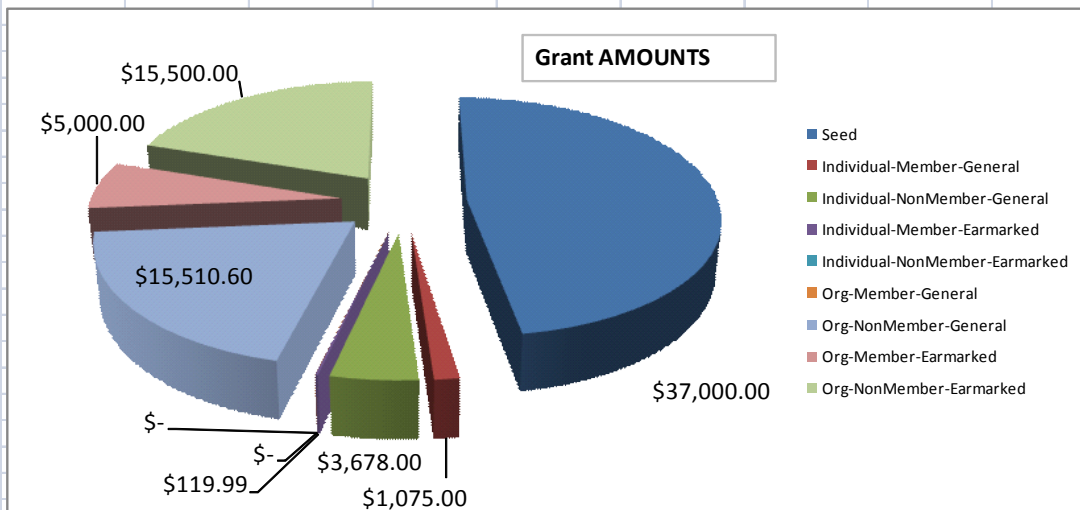


FIGURE 2

MEMBERSHIP DISTRIBUTION BY DUES CATEGORY

Member Count: Individual	Member Count: Organization	Member Count: Supporting Org	Member Count: Student	TOTAL
26	80	2	5	113

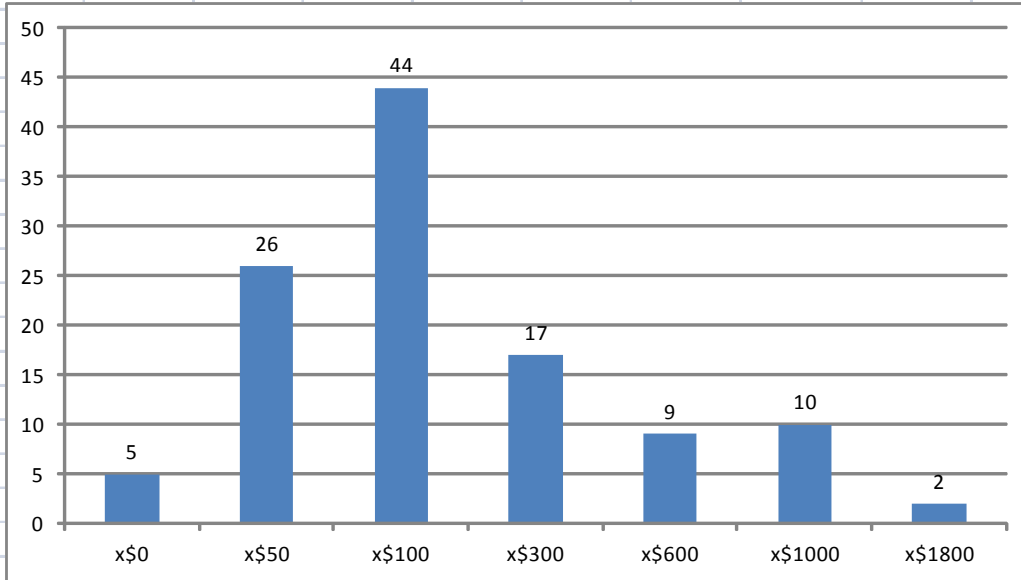
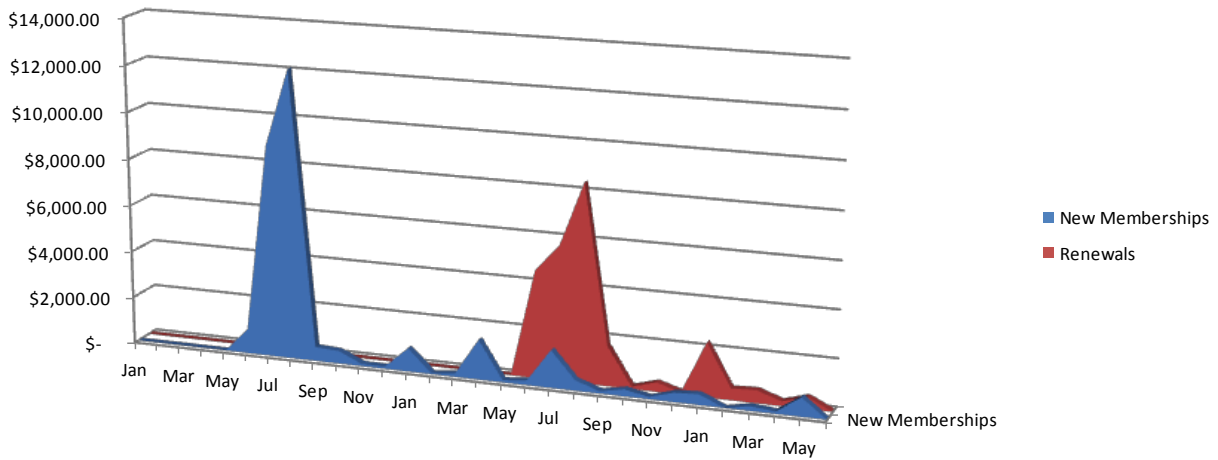
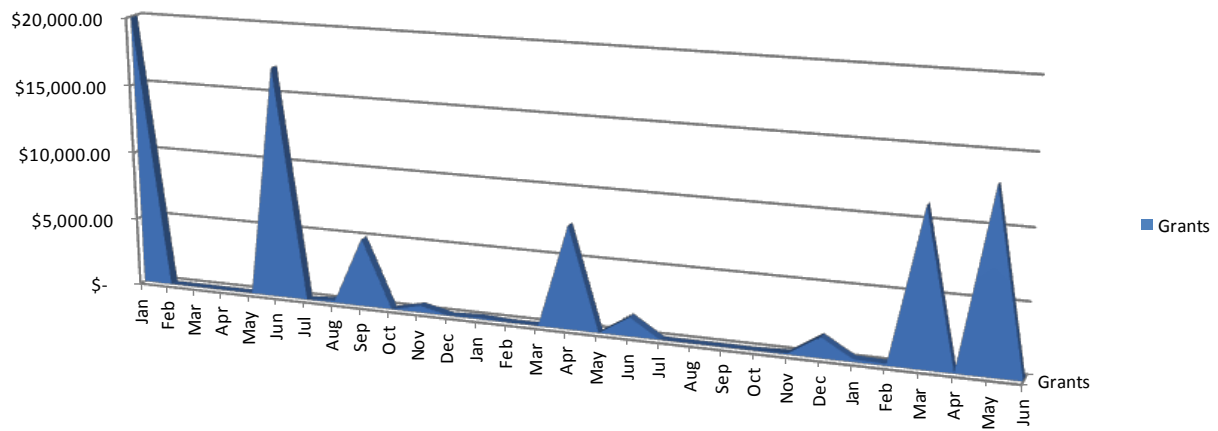


FIGURE 3A-3F

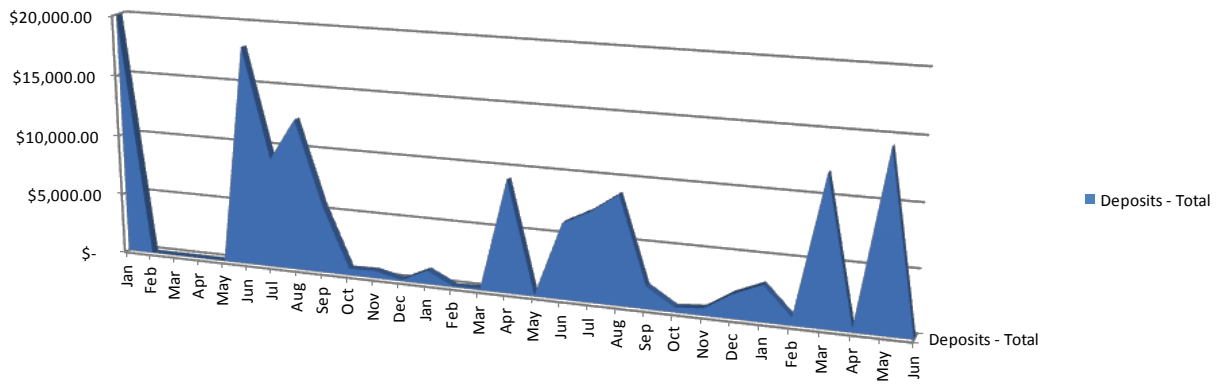
CASH FLOW GRAPHS

Please see pages 7-9.

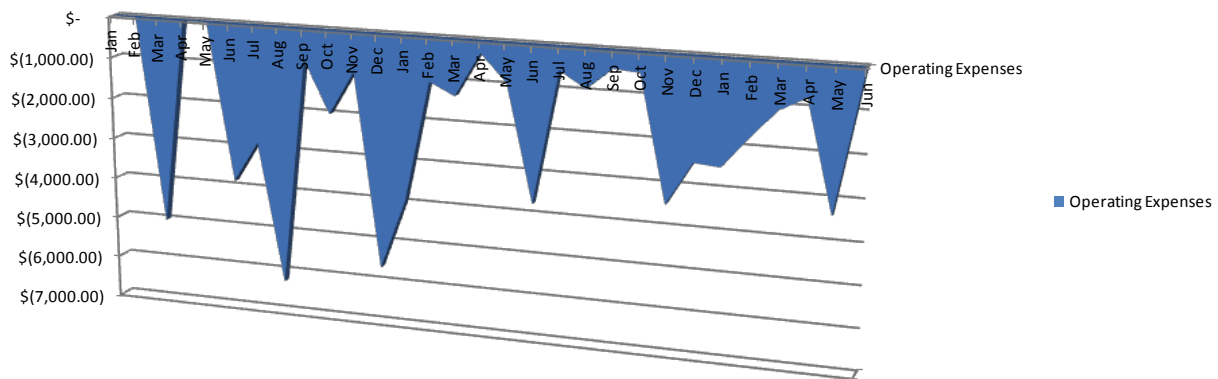
Grants



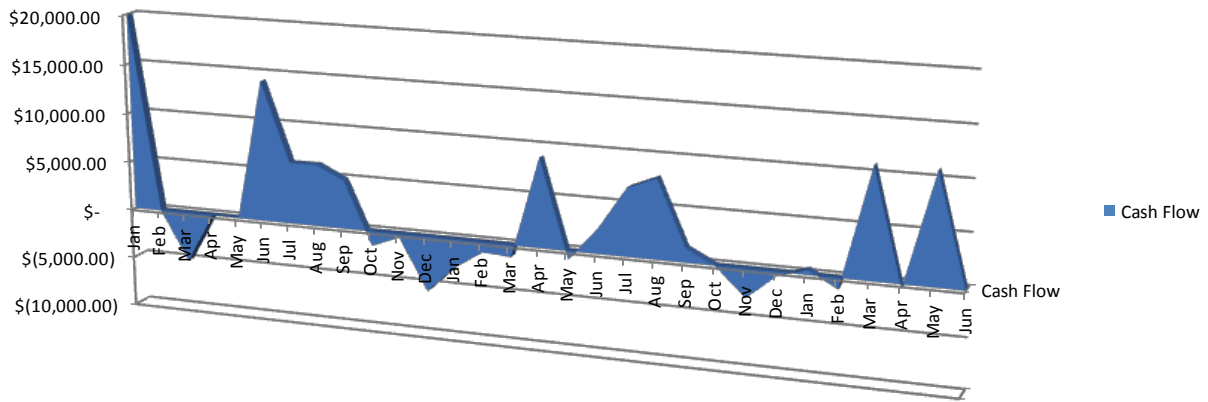
Deposits - Total



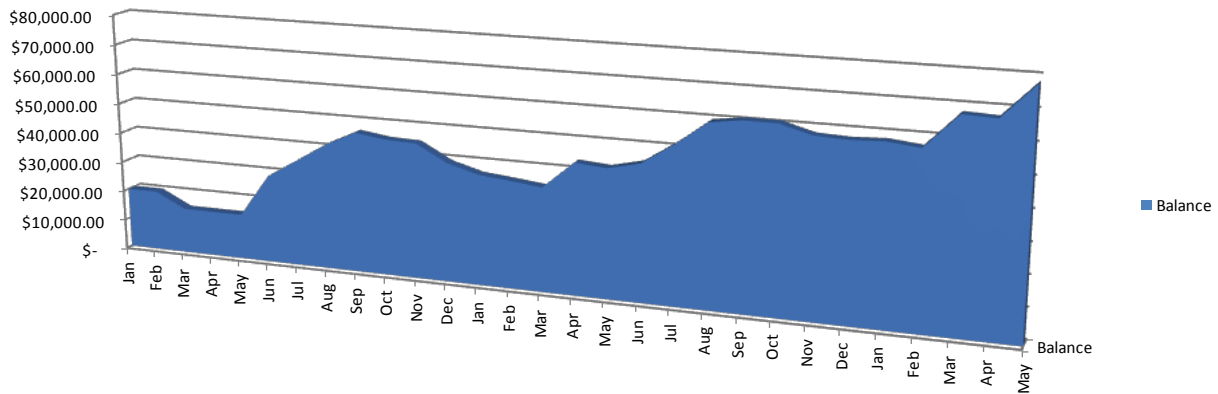
Operating Expenses



Cash Flow



Balance



2 RESEARCH PILLAR

The CAC2 Research Interest Group began this year!

Pillar Leads: Julie Sutherland, Make Some Noise: Cure Kids Cancer Foundation; Phil Renna, Christina Renna Foundation

Organizing Task Force & Group Facilitators: Trish Kriger, The Jeff Gordon Foundation for Children; Donna Ludwinski, Solving Kids Cancer; Steve Giallourakis, Steven G AYA Cancer Research Fund; Lee Marchiano, Individual Member; Deliece Hofen, Braden's Hope for Childhood Cancer; Jay Scott, Alex's Lemonade Stand Foundation; Laurie Orloski, Individual Member

Purpose Statement:

The CAC2 Research Interest Group brings together research-minded groups and individuals who are CAC2 members in good standing to advance the cause for childhood cancer research and promote the CAC2 mission of collaboration and inclusiveness through its activities.

(as adopted 4/19/15)

Summary of Activity:

A small group of research-minded facilitators gathered in the fall to help stimulate the launch of the Research Interest Group. They worked together for a few months to brainstorm, and ultimately, launch the concept of the Research Interest Group with an inaugural call and presentation on February 19, 2015.

Immediately following the inaugural meeting, the CAC2 Research Interest Group put out a survey to the membership in general with the intent to solicit feedback from those in the CAC2 community with interest in research to provide insight into members' expectations of a CAC2 Research Interest Group as well as identify volunteers to fill rotating positions. Those results enabled us to frame the interest group's governance, fill volunteer positions, and, most importantly, identify short-term and long-term objectives.

Since the initial February call, the Research Interest Group has implemented schedules for monthly group calls, tentatively planned for hosting research topic calls twice a year for the greater community, and established a very useful standing open unstructured call for members to dial in each Friday. In an effort to facilitate communication among research members, we have also established our email address and a means for the group to share information, ideas, meeting information, research news, etc., with the larger CAC2 community on Facebook.

At the time of this report, the Research Interest Group has sent out a second survey to collect data specifically from CAC2 organizations whose missions support research funding. This second survey will help us understand our research community better, assist in facilitating collaborative efforts among organizations whose funding practices are similarly aligned, and enable us to better serve both our members and the CAC2 mission.

There is great enthusiasm for the Research Interest Group. There are currently 34 members, and we hope to increase that number in the coming months and see a wonderfully active and engaged interest group evolve. We are very grateful to both the initial facilitators, and those who have since joined the group; it is through their combined efforts that the CAC2 Research Interest Group can come to fruition and help advance the cause and efforts for childhood cancer research.

Respectfully submitted by the CAC2 Research Interest Group, May 2015

research@CAC2.org

3 ADVOCACY PILLAR

Pillar Lead: Steve Crowley, Individual Member

The Advocacy Interest Group has continued to organize bi-monthly calls on a variety of current advocacy topics, issues and actions.

In September, a number of members participated in a meeting at the White House set up by the Office of Public Engagement with a presentation by Dr. Harold Varmus, head of the National Cancer Institute (NCI), and interaction with a number of public officials. Several members have maintained continued dialogue with officials from NCI, the National Institutes for Health (NIH), and other agencies as a result.

A number of members also participated in the Childhood Cancer Policy Roundtable (sometimes referred to as the Strategic Roundtable process). The Roundtable was organized by the Alliance for Childhood Cancer, and was facilitated by Dan Smith, president and founder of “AdvocacySmiths.” The goals of the process were to: convene advocates from across the community, engage in a constructive conversation, achieve clarity around common goals, and identify what cannot be agreed upon. The participants met as a large group in September, December and February, and in smaller working groups in between sessions. The Roundtable ended with a list of agreed-upon action items, the first of which was a letter to childhood cancer supporters on Capitol Hill detailing the top priorities for Appropriations funding for the coming year. The letter was signed by over 90 childhood cancer organizations (including the vast majority of CAC2 members).

CAC2 members continue to work on advocating for childhood cancer research on a number of fronts. Members of the Advocacy Interest Group are now using the CAC2 members-only Facebook page to communicate time-sensitive and other important advocacy issues and actions to other CAC2 members, and we anticipate using the features of the member portal on the CAC2 website (CAC2.org) to expand that communication. We look forward to exploring new ways to become better advocates and to help one another to reach our common goal.

4 FAMILY SUPPORT PILLAR

Pillar Lead: Angie Giallourakis, Steven G. AYA Cancer Research Fund

The Family Support Pillar needs to define its mission and objectives.

Communication – we will communicate through emails, listserves, website and facebook. We need to update our CAC2 webpage with current information about us and upcoming events.

The Family Support group would like to update all CAC2 members of its existence, learn from CAC2 members the critical issues they wish to be addressed by the support group, determine the responsibilities of each group member, etc. (For example, who will be responsible for getting the listserv up and running, who will collect listserv data). CJ Mosure (Webmaster) will help with creating the listserv.

Some Suggested Topics for Family Support:

- Helping families with newly diagnosed children
- Young children vs teenagers vs young adults (three different topics)
- Bereavement issues
- Helping siblings (younger vs older siblings)

5 MEMBERSHIP COMMITTEE

Pillar Lead: Beth-Ann Krinsky, I Care I Cure Cancer Foundation

Committee Members

Beth-Ann Krinsky—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 Member

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.

6 MEETING COMMITTEE

Pillar Lead: Joy Cruse, Team Connor

Committee Members:

Joy Cruse, Team Connor
Suzanne Nixon, Noah's Light Foundation
Karla Flook, Individual Member

Committee Charge:

Organizing the annual meetings, including January face-to-face board meeting and June all-member summit and annual meeting.

Accomplishments:

Organized and completed our annual face-to-face board meeting in January. Organizing the annual summit currently. We have the reception and meeting place scheduled. We also have hotel rooms secured for those who need them for their stay in DC. Our agenda for the meeting includes relevant and well-known speakers.

Next Steps:

Continue to finalize the details of the annual summit. Choose menu for the reception, and breakfast and lunch for the meeting. Finalize all the minor details for the meeting.

7 COMMUNICATION COMMITTEE

Committee Lead: Trish Kriger, The Jeff Gordon Children's Foundation

Committee Members

Allison Clarke, Flashes of Hope
Steve Crowley, Individual Member
Babette Ferre-Kosar, I Care I Cure Childhood Cancer Foundation
Trish Kriger, Jeff Gordon Children's Foundation
Laurie Orloski, Individual Member
Brian Riggs, Individual Member
Cynthia Van Lenten, Individual Member

Committee Charge

Membership Communication

- Create and maintain communication vehicles originating with CAC2
 - newsletter
 - e-mail notifications
 - annual/community meeting invites
- Ensure that intra-member communications adhere to established policies and guidelines

Public Communication

- Review and update content for key areas of CAC2.org, keeping content engaging and fresh
- Serve as a resources for members who are spreading the CAC2 message by reviewing materials for consistency
- Facilitate timely response to public inquiries via the website
- Establish social media strategy and maintain content
- Create a procedure to ensure timely public response to current events that impact childhood cancer
- Oversee the production of public collateral materials from draft creation through distribution of final product
- Oversee use of logo and style guide on CAC2 and member communications
- Designate media spokesperson

Accomplishments

- Published 6 Bi-Monthly Member Updates and launched new newsletter format in May 2015
- Hosted 9 webinars – total registrations 497
- Launched Social Media Platforms
 - Public Facebook Page – 599 Followers
 - Members Facebook Page – 100 Followers
 - Twitter – 105 Followers
 - LinkedIn – In Process (19 Followers)
- Produced CAC2 tri-fold brochure for use at events/mailings
- Assisted in the production and management of event communications

Next Steps

- Work with Interest Group Communications Liaisons to update and maintain CAC2 website content
- Promote public social media platforms to increase following
- Provide standardized talking points about CAC2 for all members reference
- Support all committees, projects and interest groups to provide necessary communications and marketing support
- Plan and execute public relations plan including speaker training

8 WEBSITE COMMITTEE

The CAC2 Website team is composed of the following individuals:

- Vickie Buenger, Individual Member and CAC2 President
- Angie Giallourakis: Steven G. AYA Cancer Research Fund
- Kyle Matthews: Because of Ezra
- CJ Mosure: CAC2 Web developer (contracted from Web Machine)
- Steve Pessagno: Individual Member and CAC2 Treasurer

CAC2 contracts with Web Machine, of Cleveland, Ohio, annually for maintenance of its website as well as for upgrade projects per new CAC2 business requirements. The Website Team has four key priorities for Calendar Year 2015:

1. Implement the CiviCRM platform to incorporate membership-management capabilities into the Website, thereby automating the currently manual membership processes
2. Define and implement business requirements via CiviCRM to automate CAC2 distribution-list management processes
3. Train relevant CAC2 members on CiviCRM in order for them to utilize the system to complete their CAC2 work/activities
4. Launch the member-only portal of the CAC2 Website to the entire CAC2 membership
5. Work with Interest Group subject matter experts and Committee leads to build processes to provide updated website content

Priority 1 was completed in May, and Priorities 2-5 are works in progress.

9 RESEARCH DATABASE (ICRP) – PROJECT TEAM

Project Lead: Lisa Towry, Alex’s Lemonade Stand Foundation

Committee Members

Jennifer Gowen, Luck2Tuck Foundation
Stephen Pessagno, Individual Member
Lisa Towry, Alex’s Lemonade Stand Foundation

Committee Charge

The Research Database Committee formed to explore options for sharing research funded by CAC2 members in an organized and useful way. The Committee recommended joining the International Cancer Research Partnership (ICRP) because of their existing database infrastructure, its ability to be searched and the reasonable cost. The Committee is also charged with collecting information on CAC2 member funded research projects, working with ICRP to coordinate coding, uploading the collected data into the database on an ongoing basis and providing training on how to use the database to CAC2 members.

Accomplishments

- Collected and coded over 400 funded projects from CAC2 member organizations
- Applied to become a member of the ICRP; CAC2 was accepted
- Created a process document for future funded projects uploads
- Integrated ICRP into CAC2 new member orientation
- Lisa Towry represented CAC2 at the ICRP meeting in Toronto; presented childhood cancer facts and the unique challenges our community faces as well as an overview of CAC2. As a result, the members of the ICRP are in favor of making the database searchable by childhood cancer(s). CAC2 will have the opportunity to be involved in the project. As an added bonus, ICRP and its members will be a good resource for growing our consortium and to help raise awareness about the differences between adult and childhood cancers within the general cancer community.

Next Steps

- Once CAC2 has access to the ICRP database, we will schedule a webinar to train the community on using the database as a tool (e.g., pulling data, reading reports, etc.)

10 CUREFEST – PROJECT TEAM

Project Lead: Mike Gillette, The Truth 365

Committee Members

Mike Gillette, The Truth 365

Dena Sherwood, Arms Wide Open Childhood Cancer Foundation

Bob Piniewski, People Against Childhood Cancer

Tony Stoddard, Sophia's Fund

Laurie Orloski, Individual Member

Mikelle Raffel, Ryan's Battle Buddies

Committee Charge

The primary goal of the CAC2 CureFest Committee was to establish a framework for CureFest that would allow it to become a successful annual event by and for the childhood cancer community. Secondary goals were to come up with ways to attract more childhood cancer organizations and participants to the event.

Once the Committee established the framework for CureFest it handed off the responsibility of executing the event to a Volunteer Committee made up of over 30 members of the childhood cancer community and independent advocates.

Accomplishments

CureFest 2014 was a very successful event that accomplished all of the committee's objectives. Over 75 childhood cancer foundations had informational tables at CureFest and over 250 childhood cancer groups had representatives participate. The Welcome Event at Nationals' Stadium was attended by over 600 people. The candlelight vigil at the White House had nearly 1000 participants. The CureFest Walk had over 1250 registered walkers from all 50 states. The CureFest festival had over 2500 attendees throughout the day.

Next Steps

CureFest Weekend will be held September 19 and 20, 2015. The Volunteer Committee began working on CureFest 2015 the day after CureFest 2014 was finished. The committee has a weekly teleconference and continues to follow the guidelines originally provided by the CAC2 CureFest Committee.