

Spring All-Member Webinar

March 18, 2020



CAC2
COALITION AGAINST
CHILDHOOD CANCER

AGENDA

Welcome to the CAC2 Spring All-Member Webinar

- Welcome
- 2019-2022 Strategic Plan
- Board Nomination Process
- 2020 Annual Summit
- Member Ask & Offer

- **Welcome**
- **2019-2022 Strategic Plan**
- **Board Nomination Process**
- **2020 Annual Summit**
- **Member Ask & Offer**

Our Values

...always put the children and their families *first* in everything we do.



Respect

Enable the community while respecting our members' unique missions



Efficiency

Strive for cost effectiveness and efficiency with resources



Inclusiveness

Emphasize inclusiveness and collaboration towards our common goals



Amplify

Help give voice to the community and amplify it in a coordinated fashion



Drive

Stay action-oriented and flexible

Welcome to CAC2!

31 New Members since July 1, 2019

Students (4)

Bronson Balzac
Baylor

Olivia Grischow
Ohio State Univ

Bagisha Maitra
Texas A&M

Timmy Tran
Spencerport (NY) High School

Individuals (14)

Kimberly Chiulli

Lisa Cleaton

Megan Coburn

Thaddeus Ewald

Robert Histing

Kevin Kane

Jessica Lorenz

Sarah McWhorter

Jen Merritt

Cheryl Posavac

Ann Ramer

Stanley Robbins

Barbara Solit

Nadine Shapera

Welcome to CAC2!

31 New Members since July 1, 2019

Childhood Cancer Organizations (9)

Jessie Rees Foundation: Never Ever Give Up!

Joey's Journey Foundation

Kellen's Crusade

Kier's Kids

Lighthouse Family Retreat

Live Like Lukas

Lolo's Angels

Open Hands Overflowing Hearts

Tyler Robinson Foundation

Supporting Organizations (4)

GlaxoSmithKline

Leukemia & Lymphoma Society

Making Cancer Fun

Y-mAbs Therapeutics

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CAC2 Strategic Focus Areas

Members Working Together

Support increased Interest Group activities

Promote member interactions and provide members opportunities to engage each other

Act entrepreneurially through programming opportunities

Communications

Ensure members have access to relevant, accurate, and up-to-date information

Strengthen member-to-member communication opportunities

Amplify the voice of the childhood cancer community

Operations & Sustainability

Ensure executive leadership

Build committed financial partners

Establish advisory councils

CAC2 Sustainability: By-Laws

- CAC2 by-laws limit Board service to no more than two consecutive full terms.
- CAC2 President Vickie Buenger and Treasurer Steve Pessagno will reach the end of their second consecutive full term in **June 2021**.
- Neither will be eligible for re-election for the 2021-24 Board election under current By-Laws of the organization.

CAC2 Sustainability: Operations and Financial Stability

- As President, Vickie's role encompassed BOTH board leadership and day-to-day operations management.
- As Treasurer, Steve's role encompassed BOTH establishing short- and long-term financial stability and leading development efforts to fund CAC2 operations.
- Both Steve and Vickie are VOLUNTEERS and have performed these duties in addition to holding their respective full-time paid jobs.

CAC2 Sustainability: Leadership Transition

- Leadership transition can be disruptive if not managed effectively.
- To mitigate disruption in the ongoing CAC2 mission, the Board has begun to develop a smooth, transparent, and timely transition plan.
- Services and benefits provided to CAC2 members must continue at the current high level that members expect.

Our Succession Planning Process 2020-2021

Phase 1

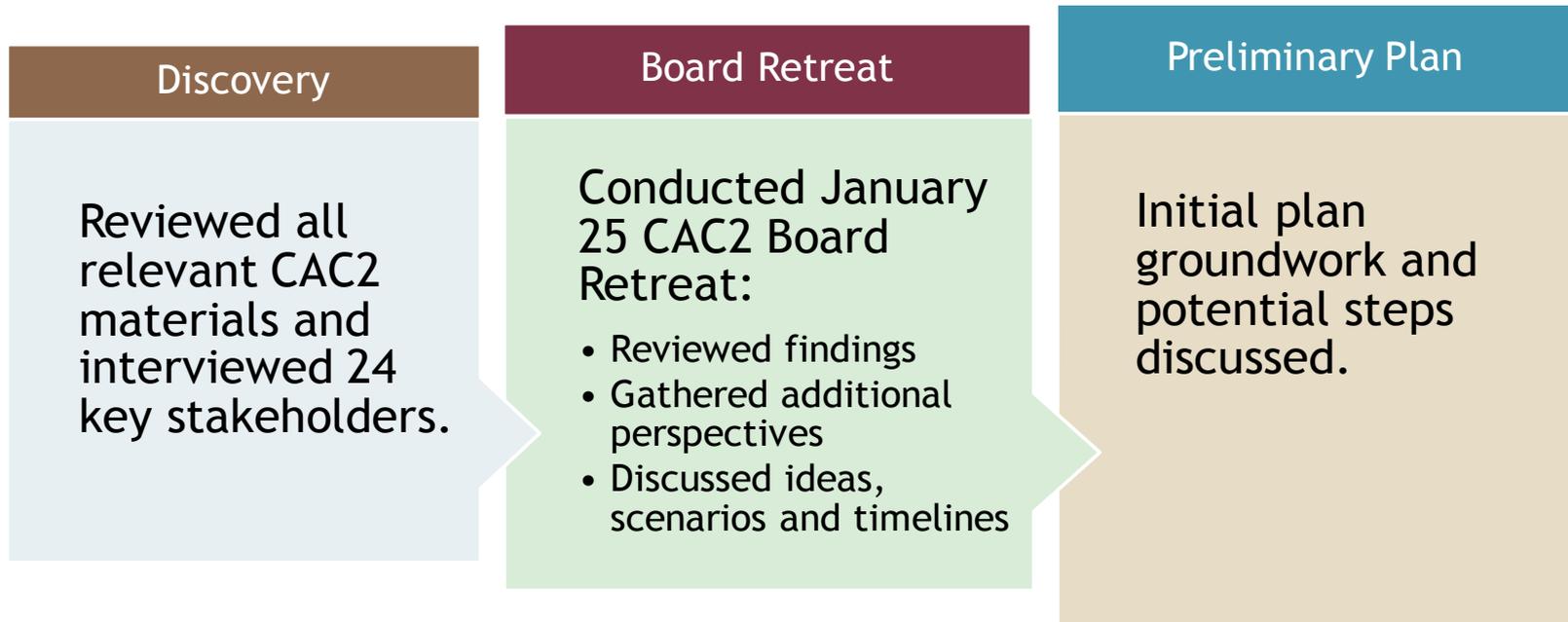
- Recognizing success to date, but acting on the need for succession
- Deciding to evolve and expand leadership

Phase 2

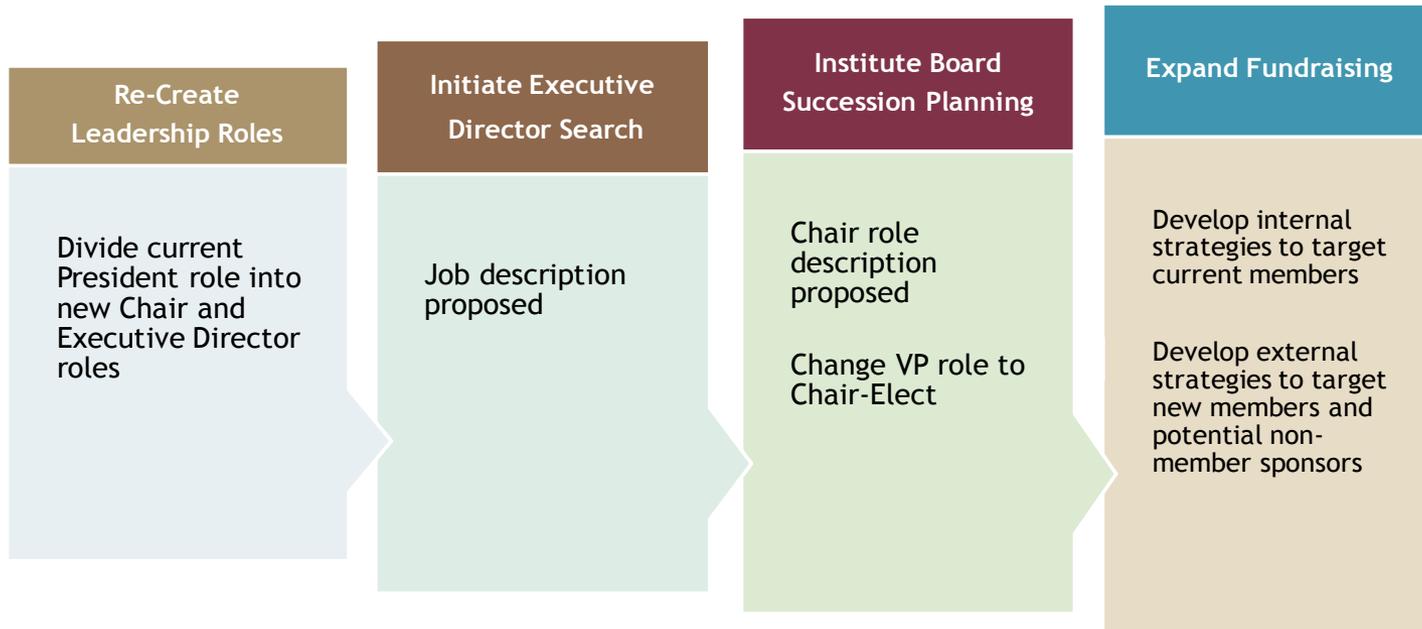
- Enabling organizational growth by expanding funding
- Engaging fundraising that doesn't conflict with CAC2 members

Securing CAC2 Future

Phase 1 is Underway

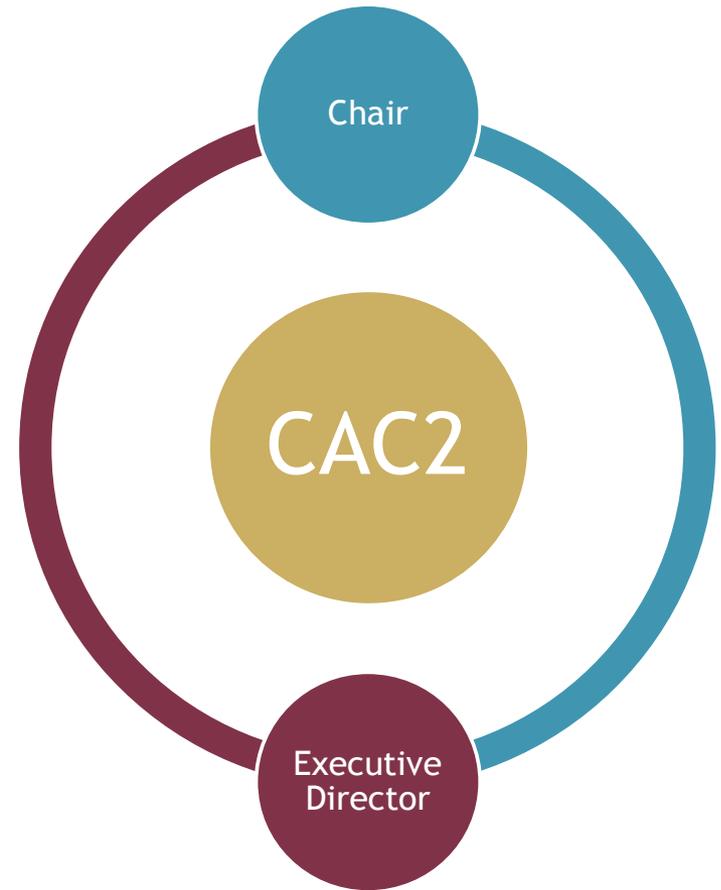


Phase 2: Proposed



Recommendation: Re-Create Leadership Roles

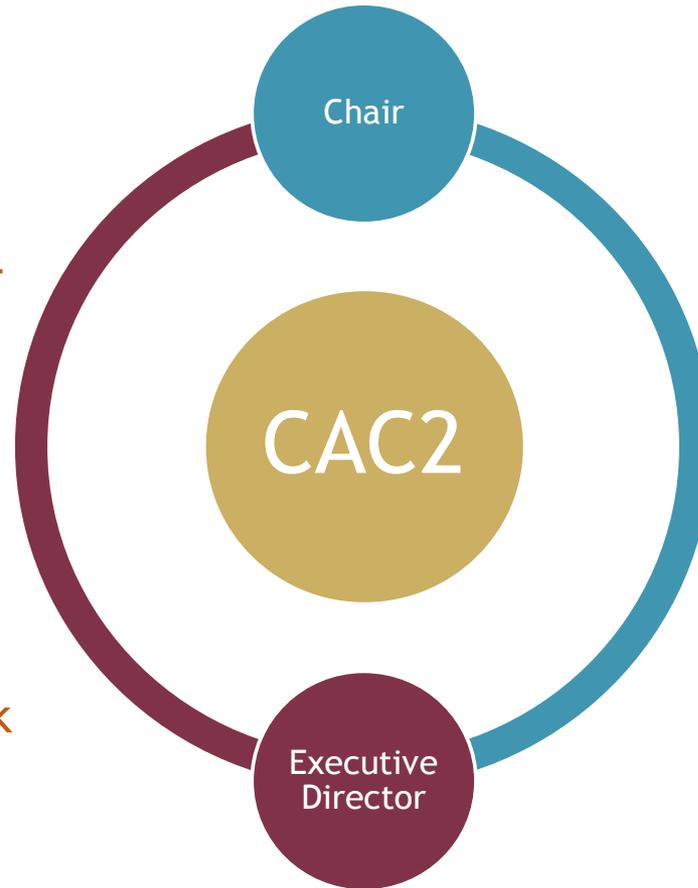
- Impractical to find a volunteer successor for Vickie in her current “President” role with her respective chair/president board and executive director responsibilities.
- Solution: Divide her current job as President into two separate and distinct roles:
 - Chair
 - Executive/Managing Director



Recommendation: Re-Create Leadership Roles

Establish a re-defined, salaried Exec/Managing Director role:

- Recruitment to begin Q4 2020
- Responsible for managing and directing all operations
- This change does not lessen the volunteer responsibilities and work of Board members.



A newly elected volunteer Chair will lead the CAC2 Board:

- A proposed role description for the Chair is being reviewed by CAC2 to aid in the recruiting of this position.

Ensuring Executive Leadership

- CAC2 Board members are and will continue to be volunteer leaders, as they are in most member organizations.
- Board elections in 2020 and in 2021 are key to CAC2's future.
- The Current Board will is committed to designing and implementing processes for sustainability, including those to identify and support executive leadership for the long-term health of CAC2.
- Board Members welcome input on potential future Board candidates, including for this year's slate.

Search Process: Executive / Managing Director

- This search will begin in Q3-Q4 2020, with the goal of the new person being contracted / hired no later than April 15, 2021.
- A Search Task Force will be developed with the responsibility to conduct the search and recommend candidates to the Board.
- To recruit and hire an Executive Director, as well as to anticipate the increased costs of a growing and successful organization as well as inflation, CAC2 must develop a plan to raise additional resources.

Treasurer Position

- Steve Pessagno will continue as Treasurer through his membership on the CAC2 Finance & Development Committee, following his departure from the CAC2 Board in June 2021.
- Due to all of the transitioning that will occur, not needing to worry about recruiting another Treasurer will allow the CAC2 Board to focus on the transition of oversight and management responsibilities from Vickie to the new Chair and Executive/Managing Director.

Step One: Board Succession Planning

Members will vote on the following by-laws change proposal at the Members meeting in Philadelphia in July.

- President → Board Chair
- Vice President → Board Chair-Elect

The Board will continue to share more details with CAC2 membership as planning continues.

QUESTIONS?

- Raise your virtual hand in the GoToWebinar Control Panel

Or

- Type your question here



GoToWebinar Control Panel

Start Broadcast

Attendees Still On Hold

Record on start

- ▶ Sharing
- ▶ Dashboard
- ▶ Attendees: 1 of 501 (max)
- ▶ Audio
- ▶ Webcam
- ▼ Questions

Show Answered Questions

Question	Asker

Type answer here

Send Privately Send To All

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Current Board Members

Board Member	Affiliation	CAC2 Board Role
Vickie Buenger	Individual Member	President
Kim Buff	Momcology	Membership Lead
Donna Criner	Northwest Indiana Cancer Kids Foundation	Development Co-Lead
Ginger Diamond	Childhood Cancer Awareness Group of Coffee County	Vice President; CAC2 Meetings Lead
Mariah Forster Olson	Neuroblastoma Children's Cancer Society	Survivorship Liaison
Angie Giallourakis	Steven G. AYA Cancer Research Fund	Family Support Liaison
Jess Kean	Children's Cause for Cancer Advocacy	Communications Lead and Advocacy Liaison
Kyle Matthews	BeatNB	Secretary; Technology Lead
Steve Pessagno	Individual Member	Treasurer; Finance and Development Co-Lead
Tom Pilko	Individual Member	Chair, Nominating Committee
Julie Sutherland	Make Some Noise: Cure Kids Cancer Foundation, Inc.	Marketing and Materials Lead
Amy Weinstein	Pediatric Brain Tumor Foundation	Assistant Secretary; Research Liaison

Board of Directors Classes and Upcoming Election Slots

Board Member	Current Year Expiry	On 2020 Slate?
Vickie Buenger	June 2021	n/a
Kim Buff	June 2022	n/a
Donna Criner	June 2022	n/a
<u>Ginger Diamond</u>	June 2020	<u>Yes</u>
Mariah Foster Olsen	June 2022	n/a
Angie Giallourakis	June 2020	Not eligible, Open seat
Jess Kean	June 2022	n/a
Kyle Matthews	June 2020	Yes
Steve Pessagno	June 2021	n/a
Tom Pilko	June 2021	n/a
Open	June 2023	Open seat
Julie Sutherland	June 2020	Not eligible, Open seat
Amy Weinstein	June 2021	n/a

2020 Board Nomination Principles

First-term board members have the option to stand for re-election at the end of their terms for a 2nd consecutive 3-year term.

CAC2 Board is a working board (no paid positions), making it important to assemble a diverse set of backgrounds and skills to set and implement an effective strategy for the Coalition, its members, and the kids and families the CAC2 membership serve.

**If you are interested in Board service,
Please email Tom Pilko: Tpp539@aol.com**

2020 Board of Directors Nomination Process

- In April and May, the Executive Committee of the CAC2 Board of Directors will assess nominations for this year's annual election of the Board of Directors.
- Candidates selected for the slate will be announced in the CAC2 June Announcements.
- Voting will be conducted on Saturday, July 18, during the CAC2 members' business meeting at the Annual Summit.
- Only Individual Members and the Voting Representative from Childhood Cancer Organization Members are eligible to vote.
- Written voting proxies are allowed for members not in attendance at the members' business meeting at the Annual Summit in July.
- Each member of CAC2 entitled to vote shall indicate support for, or opposition to, the slate of nominees.

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Coalition Against Childhood Cancer

July 16 – 18, 2020
Philadelphia



Hosted by:

Children's Hospital
of Philadelphia

Presented by:

Alex's Lemonade
Stand Foundation



AGAINST
CHILDHOOD CANCER



Meeting Overview

PRE-SUMMIT

Thursday Evening, July 16th

Meet & Greet Reception

Networking Dinner Dine-Arounds

DAY 1

Friday, July 17th

New Member Coffee Bar

Networking Breakfast

Annual Summit Program

Summit Evening Reception

DAY 2

Saturday, July 18th

CAC2 Members' Business Meeting

CAC2 Interest Group Break-Out Sessions



Meet & Greet Networking Reception

Thursday, July 16
5:00 pm - 6:30 pm

**The Study at University
City**
20 South 33rd Street



Networking Dinner 'Dine Arounds'

Thursday, July 16
7:00 - 9:00 pm

- White Dog Cafe
- Louie Louie
- Zavino
- Pod
- Distrito

Meet in small groups with other CAC2 members and CHOP researchers and clinicians over dinner at nearby Philly restaurants

You will be asked to reserve your restaurant choice when registering for the Summit.

Summit Day 1: Opening Activities

Friday, July 17

**New Member & First-Time Attendee Coffee
Bar**

8:00 am – 8:30 am

**Networking Breakfast
8:30 am - 10:00 am**

**Roberts Center for Pediatric Research
Children's Hospital of Philadelphia**

734 Schuylkill Avenue



Summit Day 1: Educational Program

Friday, July 17
10:00 am - 5:00 pm

- **Dr. Doug Hawkins:** Children's Oncology Group and a Role for Parent Patient Advocates
 - **Ellen Shohet:** The Transition to Adulthood and Health Care Responsibilities after the Childhood Cancer Experience
 - **Featured Panel:** An intimate conversation about the pediatric oncology drug development experience in companies that are putting kids first
 - **The RACE Act** on the eve of implementation
- ...and much more!

Summit Day 1: Evening Reception

Friday, July 17
Immediately following the Summit

Complimentary shuttle transportation will be available from CHOP to The Study after the reception on Friday



Summit Day 2: Business Meeting and Work Teams

Saturday, July 18
8:00 am - 3:00 pm

- Breakfast
- Inspirational Session
- Business Meeting
- Board Elections
- Working Group Sessions for Collaborative Interest Group Work

Hotel Information

The Study

20 South 33rd Street
Philadelphia PA 19104
(215) 387-1499

Room block available starting Wednesday and continuing through Sunday (July 15-19) for those with extended travel plans.

Single/Double \$199 plus applicable taxes

Complimentary Internet
Valet Parking \$40/day
Fitness Center

To book your hotel please call the hotel at 215-387-1400 and request the CAC2 2020 Annual Summit room block or utilize the web address below:
<https://reservations.travelclick.com/99716?groupID=2786298>

Please reserve your room by block deadline June 15, 2020

See you in Philly!

Register Today:

<https://www.eventbrite.com/e/2020-cac2-annual-summit-registration-92227401641>

Questions? Email meetings@cac2.org

Sponsorship and Support Opportunities

Exclusive Summit Sponsorship Opportunities Include:

- ❖ Host Sponsor – **Children’s Hospital of Philadelphia (CHOP)**
- ❖ Presenting Sponsor – **Alex’s Lemonade Stand Foundation**
- ❖ Program Book Sponsor – **Cure 4 the Kids Foundation**

Exclusive Reception Sponsorship Opportunities Include:

- ❖ Pre-Summit Meet & Greet (Thursday evening)
- ❖ Day 1 Networking Breakfast (Friday)
- ❖ Day 1 Evening Reception Sponsor (Friday) – **CHOP**

Meal Sponsorship Opportunities Include:

- ❖ Day 1 Lunch Sponsors (1 remaining; Friday) -- **Momcology**
- ❖ Day 2 Breakfast/Lunch Sponsors (2; Saturday)

Support Opportunities Include:

- ❖ CAC2 Sustaining Supporter
- ❖ Friend of CAC2

An Invitation for Sponsorship and Support

	Host	Presenting	Friday Evening Reception	Friday Networking Breakfast	Thursday Meet & Greet	Program Book	Day 1 Meals	Day 2 Meals	Coffee Reception New Members	CAC2 Sustaining Supporter	Friend of CAC2
Sponsorship Amount	CHOP	ALSF	CHOP	\$7,500	\$5,000	Cure 4 the Kids	\$2,500 Momcology	\$2,500	\$1,000	Contributions of \$500+	\$0-\$499
Opportunities Available	1	1	1	1	1	1	1	2	1	Unlimited	Unlimited
Brief Remarks at Summit	✓	✓									
Brief Remarks at sponsored reception	✓	✓	✓	✓	✓				✓		
Materials / Give-Aways at Summit	✓	✓	✓								
Name and Logo Signage at Networking Social	✓	✓	✓	✓	✓						
Name and Logo on Summit Signage	✓	✓	✓	✓	✓	✓	✓	✓	✓		
Summit Booklet Message Space	Inside Front Cover	Outside Back Cover	Half Page	Half Page	Half Page	Inside Back Cover	Half Page	Half Page	Quarter Page	Name in Summit Booklet	Name in Summit Booklet
Name & Logo on Event Webpage at CAC2.org	✓	✓	✓	✓	✓	✓	✓	✓	✓		

2020 Annual Summit

July 16 – 18, 2020

at Children's Hospital of Philadelphia

The Roberts Center for Pediatric Research

Philadelphia, PA



COALITION AGAINST
CHILDHOOD CANCER

Interested in Sponsoring or Supporting the Summit?

Contact Steve Pessagno, CAC2 Treasurer, at:

admin@cac2.org

+1.215.888.6524



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Member Ask & Offer

Cancer Prevention & Research Institute of Texas (CPRIT)

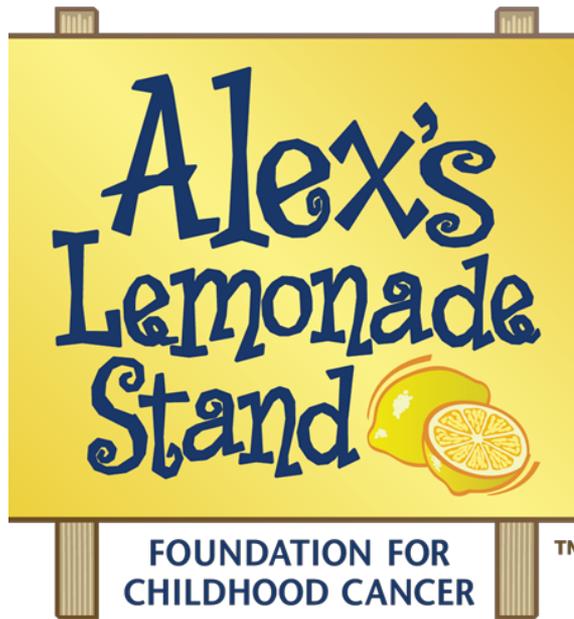
20-year \$6,000,000,000 cancer research institution
2nd largest funder of cancer research outside the US government
CPRIT has made childhood cancer research a TOP priority



Further Questions? Please Feel Free to Contact:
Annette Leslie 214-417-2155

Member Ask & Offer

Clinical Trials Navigation



- Intake form
- Touch base with family or medical professional; clarify and get details
- Review specific patient information
- Search
- Contact trials, confirm eligibility, and/or get trial suggestions
- Provide results to family or medical; if needed, refer to support services
- Follow up for outcomes or additional searches

Member Ask & Offer

CureSearch Pediatric Cancer Early Development Symposium

ADDRESSING THE COMMUNICATION GAP IN PEDIATRIC STUDY PLAN DEVELOPMENT



A **Pediatric Study Plan** is

- Outline of clinical trial
- Submitted to regulatory agencies
 - United States/FDA* – Pediatric Study Plan (PSP)
 - Europe/EMA* – Pediatric Investigational Plan (PIP)
- Pediatric Specific

Announcing the Inaugural

**CureSearch Pediatric Early Development Symposium:
Successful Planning in the New Era of iPSPs and PIPs**

October 1-2, 2020 | Boston, MA

Need: If Pediatric Study Plans are developed without the input of pediatric oncologists, important considerations for pediatric patients may not be included.

PEDS Agenda

- practical workshop for PSP/PIP development and implementation.
- a forum for discussing real-life examples and real-world lessons on a variety of topics
- seven topics with q&a + two plenary sessions
 - Chaired by industry and academic leaders from the US and EU

Thank You!

cac2.org

 @CoalitionAgainstChildhoodCancer

 @cac2org

Member Ask & Offer

Cancer Prevention & Research Institute of Texas (CPRIT)

1. [12% of CPRIT's portfolio is invested into childhood cancer research.](#)
2. Proportionately, CPRIT's commitment to childhood cancer is 3x more than the national rate.
3. Calendar years 2017 and 2018, CPRIT invested 24% of their portfolio into childhood cancer research.
4. Never in this country's history has a state put this kind of money into biomedical research.
5. CPRIT's commitment to childhood cancer research is unprecedented.
6. CPRIT is an incredible partner in our collective cause - increase funding of childhood cancer research



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Member Ask & Offer

Cancer Prevention & Research Institute of Texas (CPRIT)

7. CPRIT's research and prevention peer reviewers live and work outside of Texas.
8. CPRIT and CLF gathered over 50 investigators in and outside of TX to discuss collaborative research.
9. Members of CAC2 are recognized as collaborative leaders in the childhood cancer community.
10. CAC2/CPRIT collaborators include; but not limited to: Alex's Lemonade, Carson Leslie Foundation.
11. Direct link to CPRIT's exhaustive grant portfolio <https://www.cprit.state.tx.us/grants-funded>.
12. On portfolio page, enter one word in search box of choice to find research of interest.
13. If a research gap of interest is identified and follow-on mission driven project is of interest.
14. CPRIT's CSO, Dr. James Willson, offered CAC2 members his direct email: jwillson@cprit.texas.gov.
15. Dr. Willson is eager to answer questions and consider follow-on opportunities from CAC2 members.



Blue text: hover over sentence (which is a Website link), then right-click and select OPEN LINK.