

# Spring All-Member Webinar

## March 23, 2022



**CAC2**  
COALITION AGAINST  
CHILDHOOD CANCER

# Our Values



## 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

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



Working together today for  
a future without childhood cancers



**CAC2**  
COALITION AGAINST  
CHILDHOOD CANCER

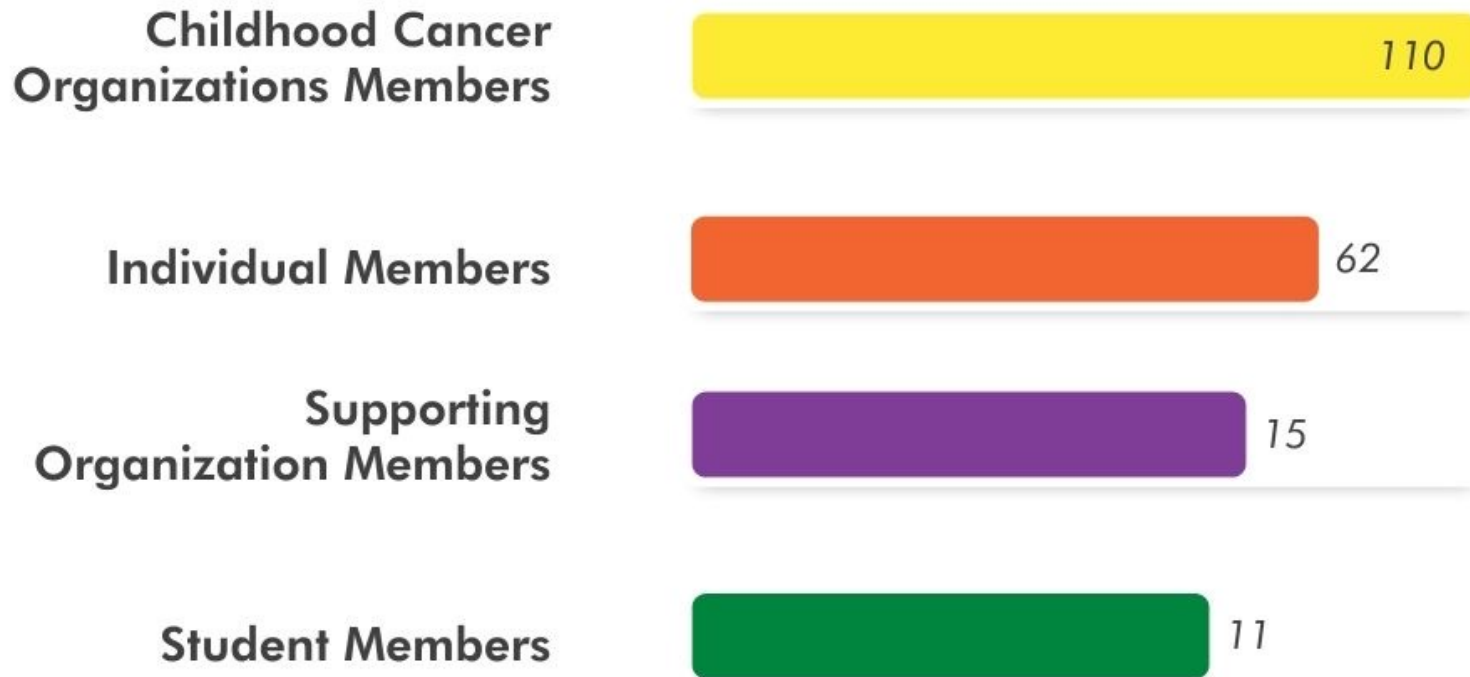
# Agenda

- Welcome
- Membership Update
- Status Update on CAC2 projects
- 2022 Annual Summit
- Strategic Plan Update
- Board Nomination Process
- Member Ask & Offer
- Volunteer with CAC2



# Membership

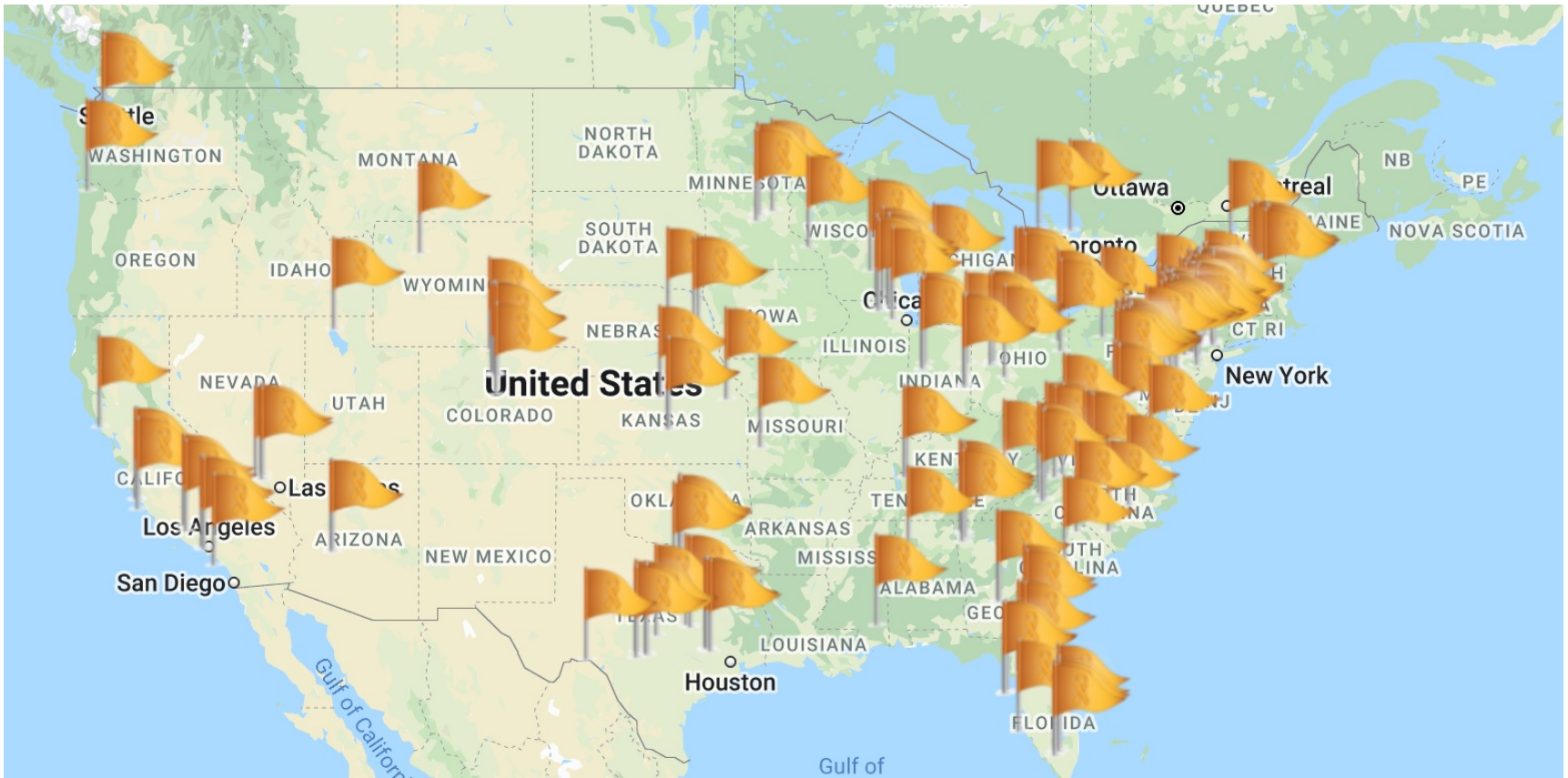
# CAC2 Membership



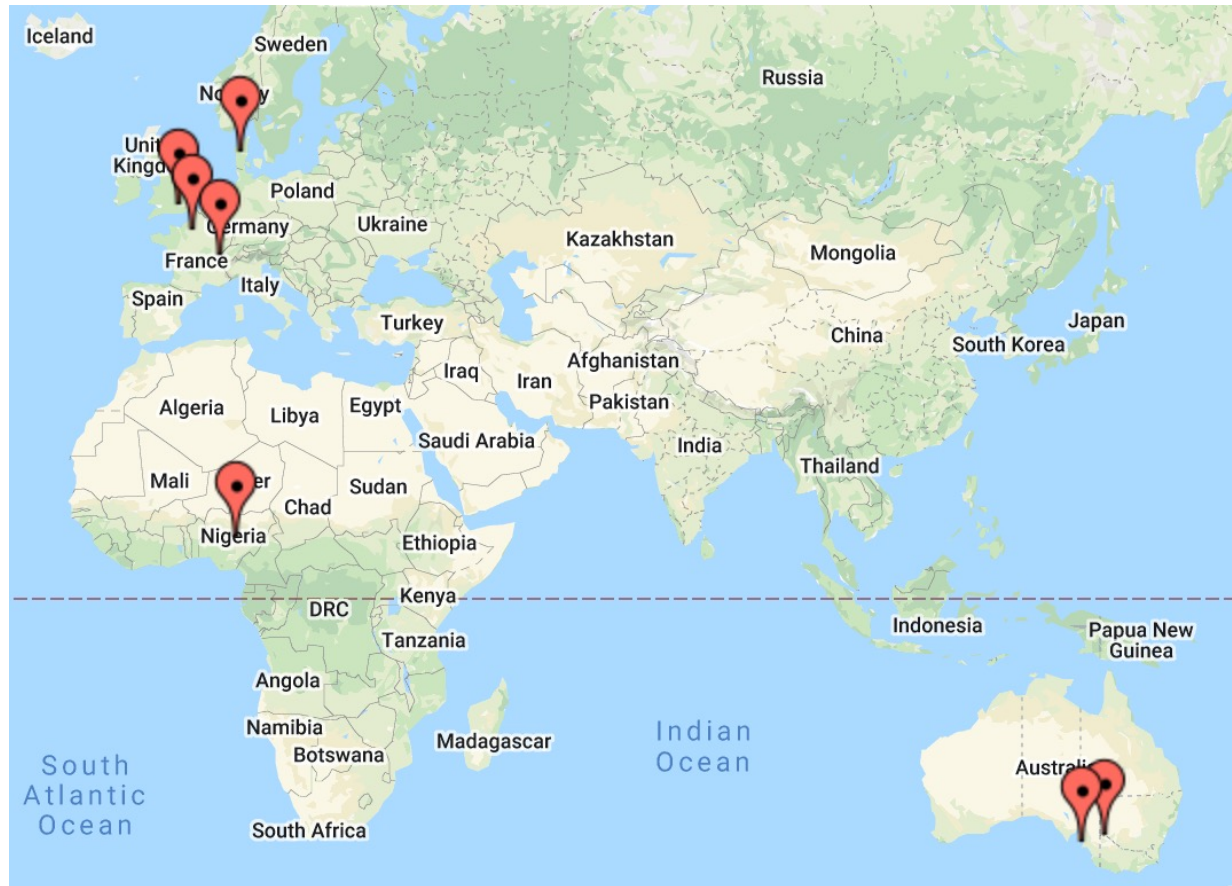
Through our organizational members, we have 248 Associate Members

# Membership

## Geographic Distribution



# Membership Geographic Distribution





# Welcome to New Members

Childhood Cancer Member Organizations	Individuals	Supporting Organizations	Students
Bearing Hope Columbus, OH	Nigel Brockton Arlington, VA	Family Reach Boston, MA	Annie Bartosz University of Pennsylvania
Connect4Cancer Encino, CA	Cathryn Carver Las Cruces, NM	The Brain Bodega Richmond, VA	Lauren Larison The University of North Carolina at Chapel Hill
Braver Stronger Smarter, Inc. Mildura, Victoria, AU	George Dahlman Richmond, VA		Serena Santoro San Diego State University
Camp Casco Sudbury, MA	Shannon Harter Hamilton, NJ		Marie Tomasula Penn State University
Love Chloe Foundation Salina, KS	Bethany Lieberman Hingham, MA		Alani Tosin Nigeria
Our Amazing Fighters Manakin Sabot, VA	Tabitha McCollum Cibolo, TX		
PREP4Gold Reston, VA	Glynnis McDonnell Arlington, VA		
So Many Angels Harmony, PA	Steven Marder Bedford, NY		
Solving Kids Cancer UK London, England	Misha Mehta Pleasanton, CA		
The Bardo Foundation Coral Gables, FL	Marc-Christian Monga Saint Cloud, France		
The Goliath Project Prior Lake, MN	Sarah Moore Fayetteville, AR		
The Smasherson Foundation Roswell, GA	Cruz Perez El Paso, TX		
Tough2gether Manhattan, KS	Billy Underwood Houston, TX		
	Tara Waters Weymouth, MA		



Putting Children and Families First in Everything We Do

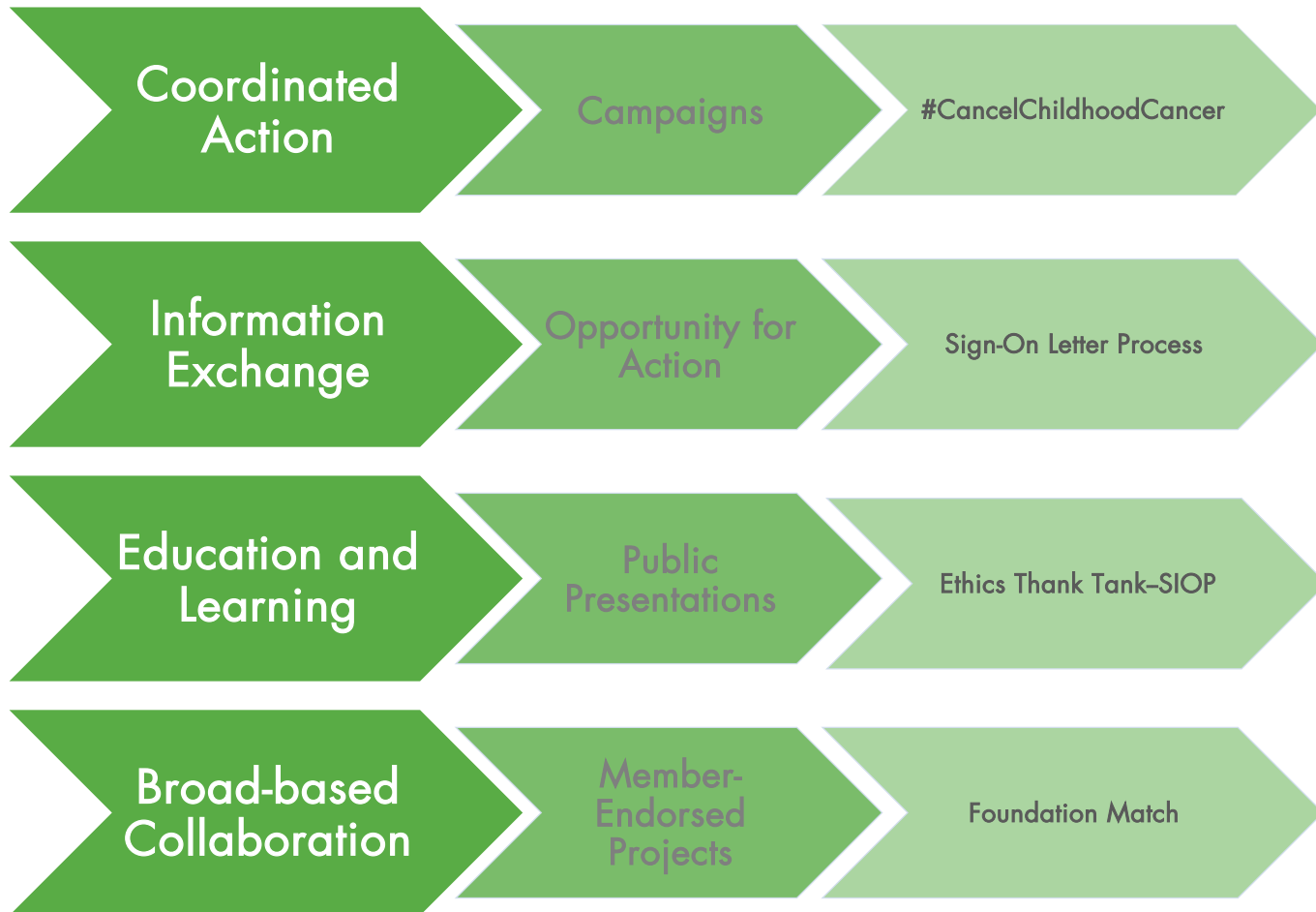
**Hello Mandy Spielvogle Powell, welcome to the CAC2 Member Hub!**

You have access to member resources as part of your CAC2 membership. Bookmark this page and return often for updates, resources, and to connect with fellow members.

- CAC2 News, Blogs, Webinars and Community Highlights
- Interactive Member Map
- Submit Speaker Ideas for Webinars
- Collaborative Work Space
- CAC2 Resources & Information

# CAC2 Projects

# Current Examples of CAC2 Mission in Action





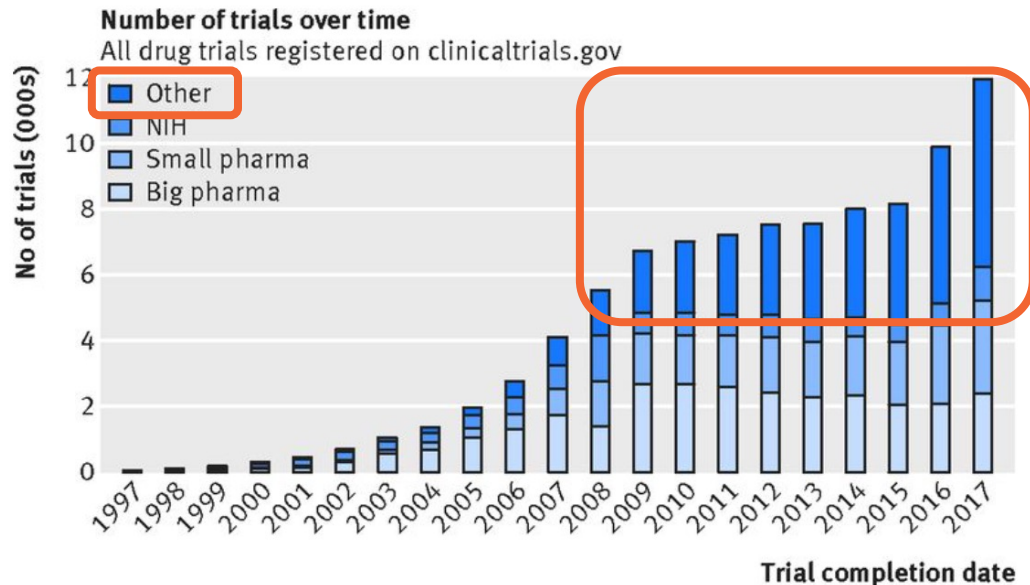
# RIG: Ethics Think Tank

Project Aim: To develop a working paper identifying both the potential ethical issues charities face when funding research as well as the suggested best management practices (BMPs) charities may use in dealing with those issues.

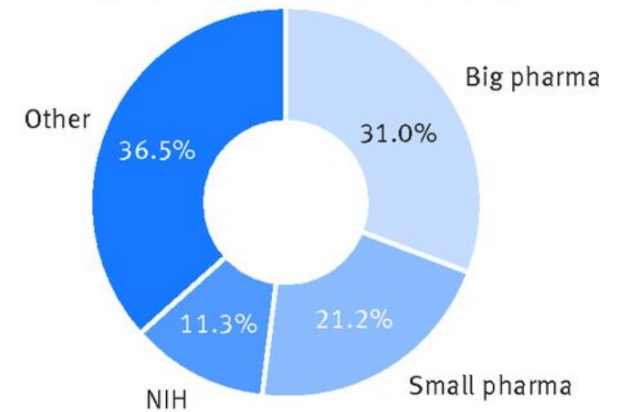
# RIG: Ethics Think Tank Team

- Caitlyn Barrett, CureSearch
- Vickie Buenger, Individual Member
- Cindy Campbell, Ty Louis Campbell Foundation
- Robin French, The Morgan Adams Foundation
- Donna Ludwinski, Solving Kids' Cancer
- Vasiliki Rahimzadeh, Postdoctoral Fellow, Stanford Center for Biomedical Ethics
- Amy Weinstein, Pediatric Brain Tumor Foundation
- Susan Wolfert, Taylor Mathews Foundation

# RIG: Ethics Think Tank

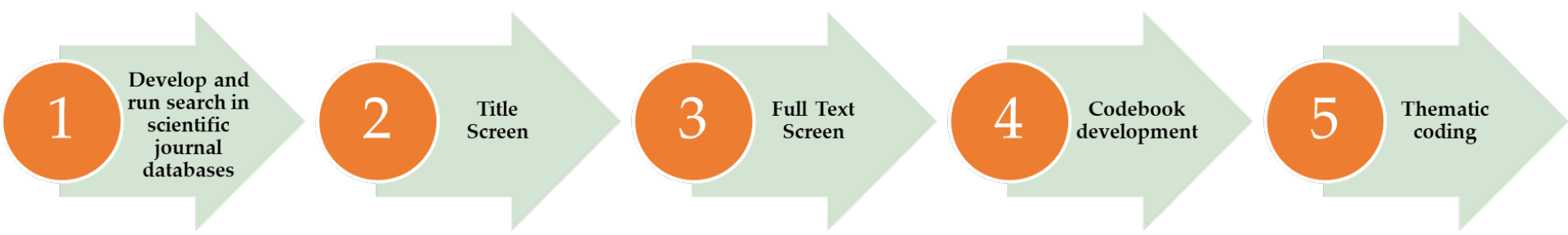


**Overall distribution of trial funding source**  
All drug trials registered on clinicaltrials.gov



What are the ethical obligations of charitable organizations to the following stakeholder groups when funding pediatric clinical trials

- Patients and families
- Donors
- Researchers
- Sponsors

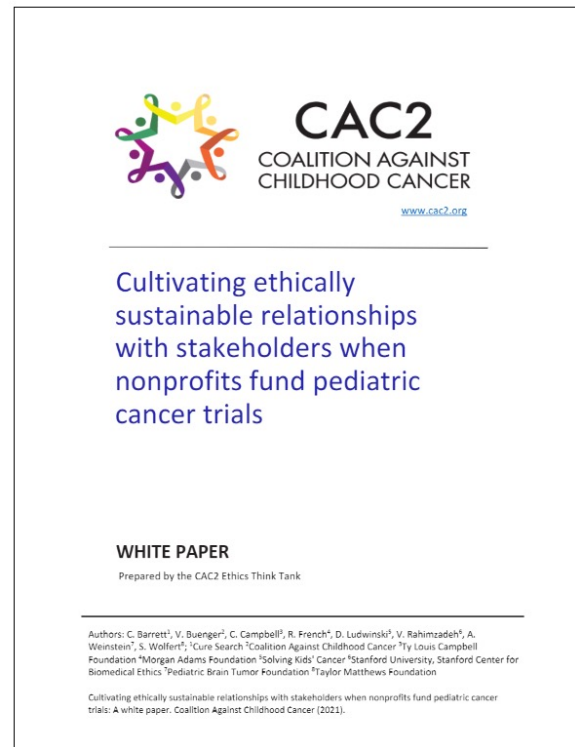


8-member team engaged in Steps 1-4

3-member team engaged in Step 5

# Progress and Wins

## Ethics Think Tank White Paper



**CAC2**  
COALITION AGAINST  
CHILDHOOD CANCER  
[www.cac2.org](http://www.cac2.org)

**Cultivating ethically sustainable relationships with stakeholders when nonprofits fund pediatric cancer trials**

**WHITE PAPER**  
Prepared by the CAC2 Ethics Think Tank

Authors: C. Barrett<sup>1</sup>, V. Buenger<sup>2</sup>, C. Campbell<sup>3</sup>, R. French<sup>4</sup>, D. Ludwinski<sup>5</sup>, V. Rahimzadeh<sup>6</sup>, A. Weinstein<sup>7</sup>, S. Wolfert<sup>8</sup>; Cure Search<sup>9</sup>, Coalition Against Childhood Cancer<sup>10</sup>, Ty Louis Campbell Foundation<sup>11</sup>, Morgan Adams Foundation<sup>12</sup>, Solving Kids' Cancer<sup>13</sup>, Stanford University<sup>14</sup>, Stanford Center for Biomedical Ethics<sup>15</sup>, Pediatric Brain Tumor Foundation<sup>16</sup>, Taylor Matthews Foundation<sup>17</sup>

Cultivating ethically sustainable relationships with stakeholders when nonprofits fund pediatric cancer trials: A white paper. Coalition Against Childhood Cancer (2021).

## Ethics Think Tank Presentation, SIOP 2021



CAC2 Bioethics SIOP Presentation, October 2021

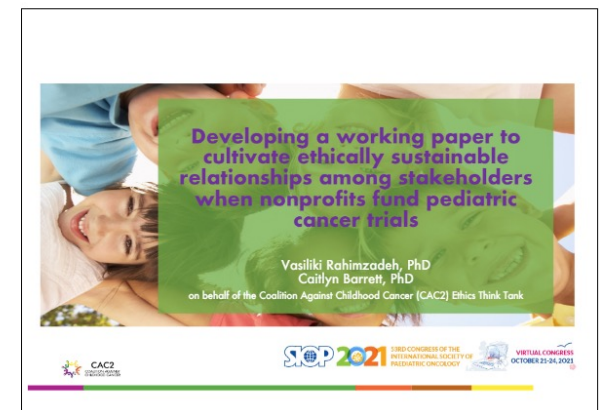
Share

CAC2 Ethics Think Tank Project Aim

To develop a working paper identifying both the potential ethical challenges facing pediatric cancer research as well as solutions (BAPs) needed

Watch on YouTube

## Ethics Think Tank Slide Deck



**Developing a working paper to cultivate ethically sustainable relationships among stakeholders when nonprofits fund pediatric cancer trials**

Vasiliki Rahimzadeh, PhD  
Caitlyn Barrett, PhD  
on behalf of the Coalition Against Childhood Cancer (CAC2) Ethics Think Tank

CAC2 COALITION AGAINST CHILDHOOD CANCER

SIOP 2021 33RD CONGRESS OF THE INTERNATIONAL SOCIETY OF PEDIATRIC ONCOLOGY

VIRTUAL CONGRESS OCTOBER 23-24, 2021



# Progress and Wins

- Scientific publication in production by ethicist and the team to be submitted to Pediatric Blood & Cancer
- Working group is determining next steps, if appropriate

Thank you!

Funding support provided by Steve Passagno and the Elaine Roberts Foundation

Thanks to the Ethics Think Tank Member organizations who graciously shared their employees for the project.

# Campaign Goals

July 2020- September 2022

## Cancel Childhood Cancer

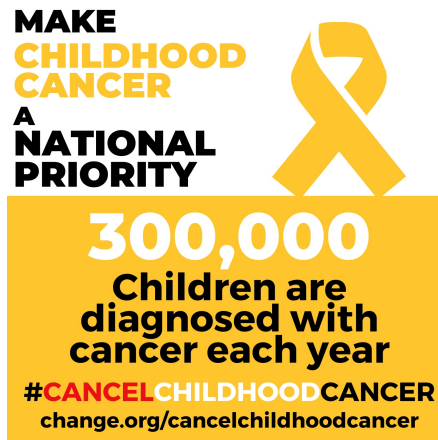
- Promote the Cancel Childhood Cancer petition initiated by Rene Marsh – Gather signatures
- Increase Awareness for Childhood Cancer Initiatives
- Rally the childhood cancer community into one cohesive group focused on a specific goal

# Highlights

## Tool Kit Provided to Members



At Curefest attendees from throughout the community took pictures with the campaign frame



Childhood Cancer Facts were shared across social media platforms several times a week



Over 6,000 Used The Frame

# 2022 Annual Summit





# CAC2 Annual Summit

## Together, Forward

**June 21 - 23, 2022**

Host: Children's Hospital of Philadelphia

Presenting Sponsor: Day One Biopharmaceuticals



# 2022 Annual Summit Overview Together, Forward

## June 21

5:00 pm - 6:30 pm

Meet & Greet Networking Social

7:00 pm - 9:00 pm

Networking Dinner Dine-Arounds

## June 22

8:00 am - 5:30 pm

Annual Summit Education & World Café

5:30 pm - 7:00 pm

Member Social

## June 23

8:00 am – 3:00 pm

Annual Business Meeting  
Interest Group Break-Outs

## Keynotes

- ✓ **Dr. Danielle Carnival, Cancer Moonshot Coordinator and Senior Advisor to the White House OSTP** What is the reignited Cancer Moonshot? Where does childhood cancer fit in the seven pillars to progress and what can the childhood cancer community do to help realize the potential of this collective effort?
- ✓ **Dr. Doug Hawkins, Seattle Children's** How can we ensure greater access to available therapies and clinical trials?

## Speakers

- ✓ **Dr. Stephanie Dixon, St. Jude** Is 5-Year survivorship the right metric for childhood cancer?
- ✓ **Dr. Brigitte Widemann, Chief, Pediatric Branch, National Cancer Institute** What is the Childhood Cancer Data Initiative and what can the childhood cancer community do to help realize the potential of data?

## Advocacy Briefs

- ✓ **Dr. Greg Reaman, FDA** Race Act 2022 (pending agency review)
- ✓ **Sarah Milberg, Alliance for Childhood Cancer** What the Childhood Cancer Community Needs to Know about "More Than Four"



## Panel Discussions

- ✓ **International Collaboration** Why is Intercontinental/international cooperation important to progress for pediatric cancer?
  - ✓ Lia Gore, Colorado Children's Hospital
  - ✓ Pam Kearns, University of Birmingham, UK
  - ✓ Sarah Alexander, Sick Kids Hospital, Canada
  - ✓ Dominik Karres, European Medicines Agency
  - ✓ Greg Reaman, Food and Drug Administration (pending agency approval)
- ✓ **Educational Planning** What do parents and organizations need to know about Educational Planning (during treatment and beyond)?
  - ❑ CHOP-led (Lamia Barakat and team, in process)



## Hotel Blocks

### **Sheraton Philadelphia University City Hotel**

\$159 / night

Block available 6/20/2022 - 6/23/2022

Hotel block closes on June 1, 2022

### **The Study at University City**

\$219 / night

Block available 6/21/2022 - 6/24/2022

Hotel block closes on May 22, 2022



# Register Today!

Register online at <https://cac2.org/2022-annual-summit/>

Registration is complimentary for all CAC2 Members

Questions? Email [meetings@cac2.org](mailto:meetings@cac2.org)

**CAC2 Annual Summit 2022**

June 21-23, 2022

**Hosted by the Children's Hospital of Philadelphia**

# Coalition Against Childhood Cancer

**Roberts Center for Pediatric Cancer Research**

734 Schuylkill Avenue | Philadelphia PA 19146





HOST SPONSOR

PRESENTING SPONSOR



## 2022 Annual Summit Sponsors



# 2022 Sustaining Supporters

Grants and Donations \$500+



**Joe Canuso**

**Jaime L. Howard**

**Steven L. Pessagno**

**Matt C. Taylor**

## 2022 Friends of CAC2

Grants and Donations \$1 - \$499

# 2022 Sponsorship and Support Opportunities

	Presenting Sponsor	Main Reception	Summit Education Program	Program Book	Meet & Greet Reception	World Café Sessions	Interest Group Sessions	Lunch Sponsors	Breakfasts & Breaks Sponsors	Transportation Sponsor	Volunteer of the Year Award	CAC2 Sustaining Supporter	Friend of CAC2
Amount	Day One Bio	Children's Hospital of Philadelphia	Y-mAbs Therapeutics	\$6,500	Oncoheroes Biosciences	Morgan Adams Foundation	\$2,500	\$2,500	\$1,500	\$1,500	Andrew McDonough B+ Foundation	Donations of \$500+	Donations \$0-\$499
Opportunities Available			1	1	1		4	2	2	1		Unlimited	Unlimited
Brief Remarks at Kick-Off: Each Day of Summit	✓												
Brief Remarks at Sponsored Section of Meeting		✓	✓		✓	✓	✓						
Pre-Summit Mailing with Program Book: Materials Inclusion	✓	✓	✓										
Name and Logo on all Summit Communications	✓	✓	✓										
Name & Logo on Event Webpage at CAC2.org	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Summit Booklet Message Space	Outside Back Cover	Inside Front Cover	Full Page	Inside Back Cover	Full Page	Half Page	Quarter Page	Quarter Page	Quarter Page	Quarter Page	Half Page	Name in Summit Program Book	Name in Summit Program Book

Grants and donations by Sponsors, Supporters, and Friends of CAC2 will help defray operating expenses for the summit and/or support the mission of CAC2 throughout the year.

Thank you!

# Benefits of 2022 Annual Summit Sponsorship

1

## Branding & visibility among 150+ representatives of the childhood cancer community, including:

- **Executive Directors** and decision makers of childhood cancer philanthropies
- **Individual advocates**
- **Bench scientists**, sharing advances in laboratory studies and discoveries
- **Clinical researchers and medical practitioners**, sharing treatment impact and bench-to-bedside outcomes
- **Government officials**, sharing legislative and policy updates
- **Corporate and industry executives**, representing organizations that have a direct or indirect interest in childhood cancer issues

2

## Participation in the CAC2 Annual Summit, including networking activities and education program

3

## Meeting and connecting with advocates, change-agents, funders, and community leaders

## 2022 Annual Summit

June 21-23, 2022

Children's Hospital of Philadelphia | Roberts Center for Pediatric Research  
Philadelphia, PA

# Interested in Sponsoring or Supporting the Summit?

Contact Steven L. Pessagno, CAC2 Treasurer:  
[admin@cac2.org](mailto:admin@cac2.org) | 215.888.6524 | [www.CAC2.org](http://www.CAC2.org)



[@CoalitionAgainstChildhoodCancer](https://www.facebook.com/CoalitionAgainstChildhoodCancer)



[@cac2org](https://twitter.com/cac2org)

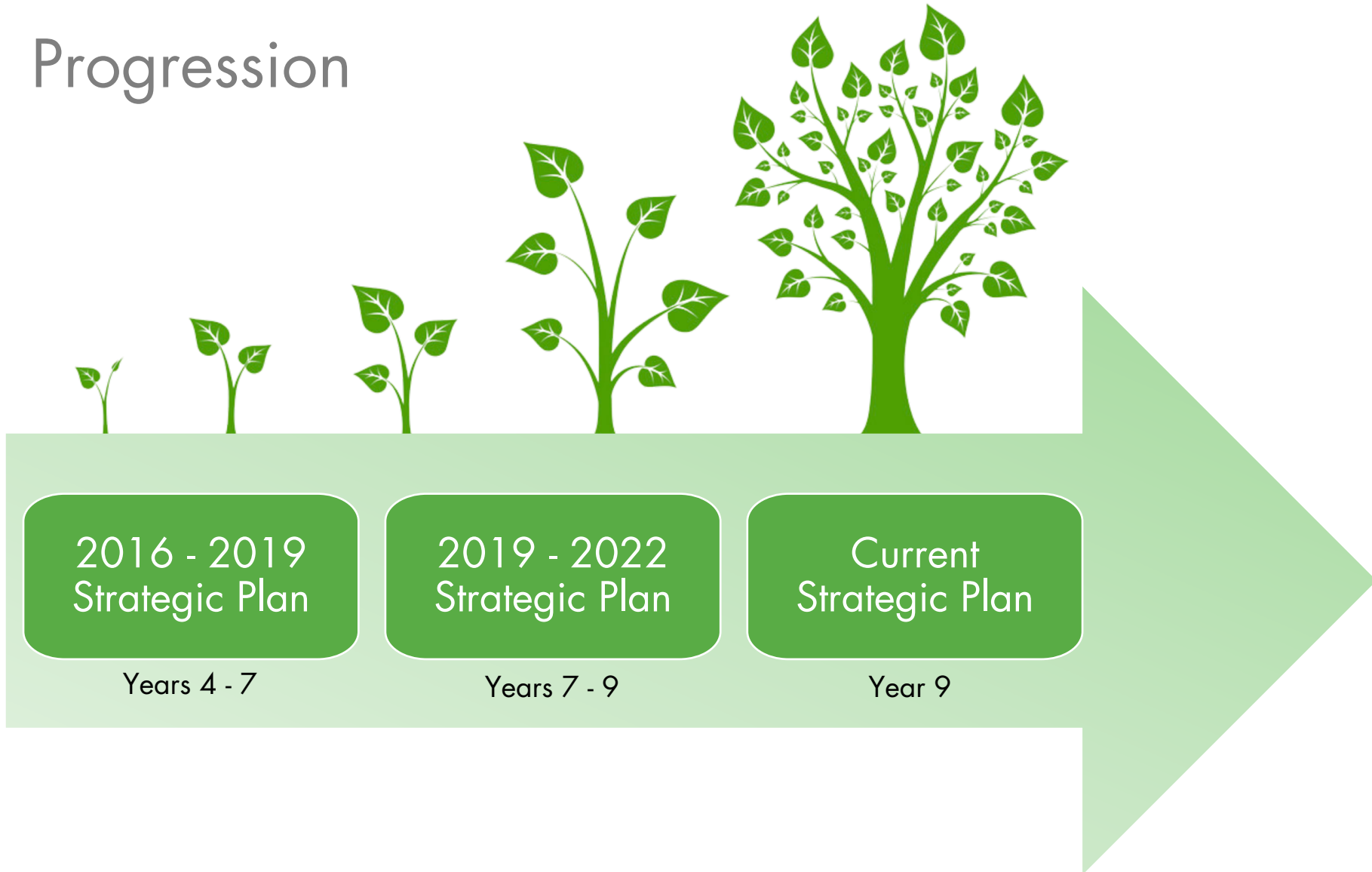


**CAC2**  
COALITION AGAINST  
CHILDHOOD CANCER

# CAC2 Strategic Plan



# Progression





# Strategic Planning Process

- Audit with consultation from outside professional
- Strategic Planning Board workshop facilitated by external consultant
- Board review and approval of new Strategic Plan Focus Areas/Tactics
- Mapping of existing/current and proposed projects to ensure strategic alignment
- Sharing of Strategic Plan with CAC2 Members



**CAC2**  
COALITION AGAINST  
CHILDHOOD CANCER



## Guiding Principles

- Trustworthiness and credibility
- Shared goals
- Broad and diverse members working together
- Collective unity
- Inclusiveness
- Ability to activate grassroots to action
- Trusted partner



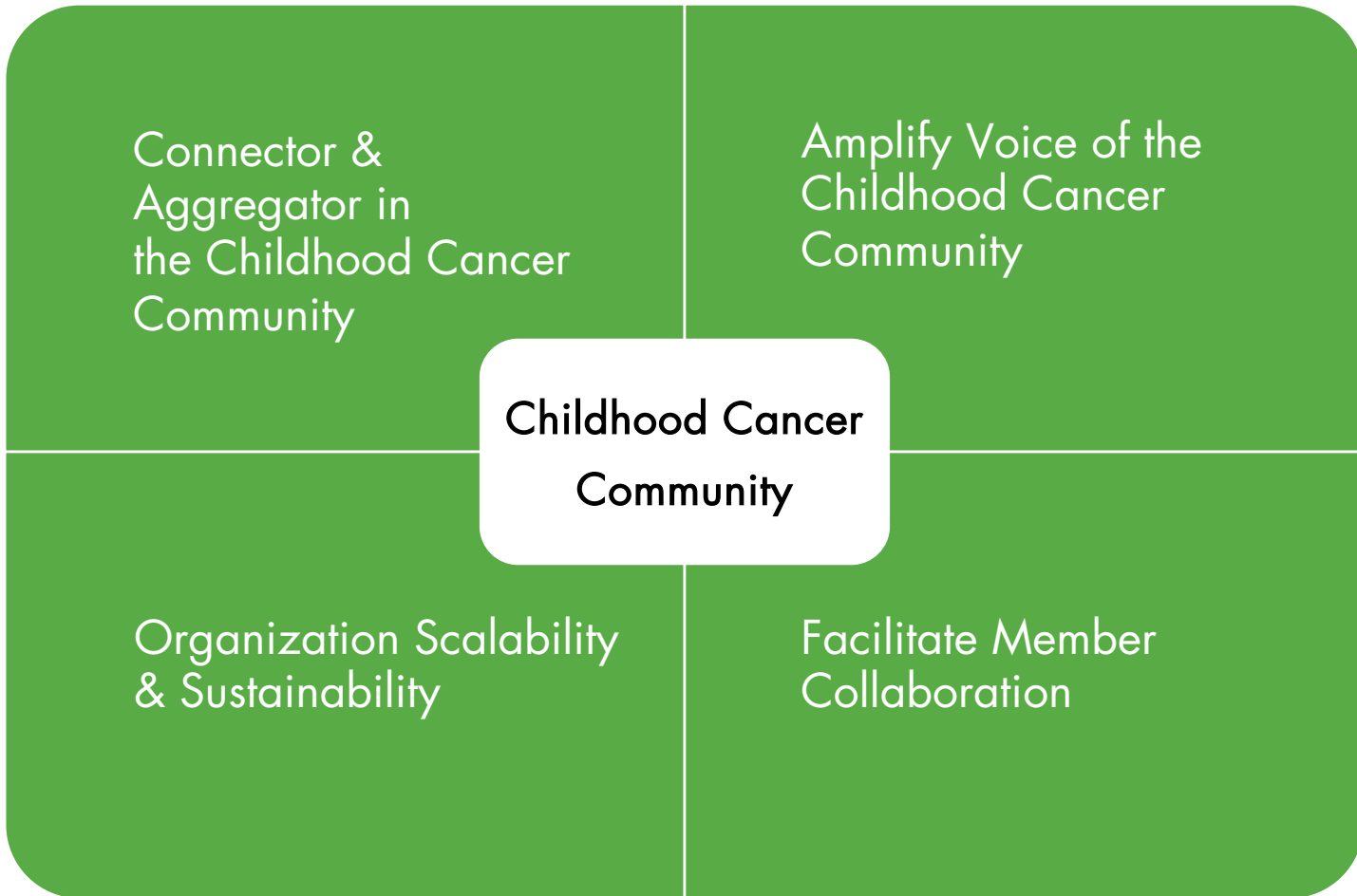
**CAC2**  
COALITION AGAINST  
CHILDHOOD CANCER



# Confirmed Challenges

- Finding non-competitive financial support
- Encouraging engagement and contribution amongst members
- Communicating clearly and in a timely way
- Weighing emerging opportunities
- Enabling processes for members to work together

# Strategic Plan Key Focus Areas



# Board Nomination Process

# Current Board Members

**Amy Weinstein\***, Board Chair

Pediatric Brain Tumor Foundation

**Amy Godkin\***, Vice Chair and Family Support Liaison

ASK Foundation

**Mariah Forster Olson\***, Secretary and Survivorship Liaison

Neuroblastoma Children's Cancer Society

**Sarah Bartosz\***, Leadership Success Liaison

Beat Childhood Cancer

**Ginny McLean\***, Project and Campaign Oversight

Swiftly Foundation

**Caitlyn Barrett**, Research Liaison

CureSearch for Children's Cancer

**Jeremy Bliler**, Technology Lead

Gold Rush Cure Foundation

**Ginger Diamond**, Hospitality Lead

Childhood Cancer Awareness Group of Coffee County

**Robin French**, Webinar Lead/Nominating Co-Lead

The Morgan Adams Foundation

**Jess Kean**, Awareness Liaison

Children's Cancer Cause

**Angela Lee**, National Advocacy Liaison

Individual Member

**Kim MacNeill**, Membership Lead

Ross K. MacNeill Foundation

**Ann Ramer**, State Advocacy Liaison

Individual Member

**Steve Pessagno**, Treasurer and Development Lead (ex officio)

Individual Member

**Vickie Buenger**, President Emeritus (ex officio)

Individual Member

\*Executive Committee

# Board of Directors Classes & Upcoming Election Slots

Board Member	Current Term Expiry	On 2022 Slate?
Caitlyn Barrett	2022	Yes, Completed 1 Year Term
Sarah Bartosz	2023	n/a
Jeremy Bliler	2023	n/a
Ginger Diamond	2023	n/a
Robin French	2024	n/a
Amy Godkin	2023	n/a
Jess Kean	2022	Not eligible. Open Seat
Angela Lee	2024	n/a
Kim MacNeil	2024	n/a
Ginny McLean	2022	Yes, Completed 2 Year Term
Mariah Olson	2022	Yes, Completed 3 Year Term
Ann Ramer	2024	n/a
Amy Weinstein	2024	n/a



# CAC2 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 Robin French:  
[robin@morganadamsfoundation.org](mailto:robin@morganadamsfoundation.org)

# Nomination and Voting 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 Thursday, June 23, 2022, 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 June.
- Each member of CAC2 entitled to vote shall indicate support for, or opposition to, the slate of nominees.

# Ask & Offer



ALLIANCE FOR CHILDHOOD CANCER  
ACTION DAYS

[www.allianceforchildhoodcancer.org](http://www.allianceforchildhoodcancer.org)

Virtual Trainings and Meetings

April 28, 2022

All Childhood Cancers

Sign Up Deadline: April 8, 2022



[www.braintumor.org](http://www.braintumor.org)

Hybrid format:

Both In-Person and Virtual Training

Virtual Hill Meetings

May 2-3, 2022

Pediatric and Adult Brain Tumors

Sign Up Deadline: April 8, 2022



## RESEARCHERS ROUNDUP

*together, helping kids fight cancer*

CONVENE CONFERENCE CENTER

3000 Pegasus Park Lane

Dallas, Texas 75247

July 24-26, 2022

Cancer Prevention & Research  
Institute of Texas

&

Carson Leslie Foundation  
are Rounding Up

Texas' Brightest Childhood Cancer Investigators  
to

Discuss | Identify | Encourage  
COLLABORATION

Outcome of Researchers RoundUp  
will help frame CPRIT's Childhood Cancer RFA's

[RESEARCHERS ROUNDUP 2020 video](#)

[annette@carsonlesliefoundation.org](mailto:annette@carsonlesliefoundation.org)

# Thank You!

[cac2.org](http://cac2.org)

 @CoalitionAgainstChildhoodCancer

 @cac2org