

**PROJECT DESCRIPTION:  
PROPOSED CAC2 PROJECT, JANUARY 2019**

The following describes a proposed new project submitted to the CAC2 Project Incubator by members of the Research Interest Group. The project title is

**CAC2 Think Tank:  
Exploring the Potential Ethical Issues & Best Management Practices  
for Childhood Cancer Charities Funding Research**

One of the main ways that CAC2 supports the childhood cancer community is by identifying and completing projects that individual organizations can't do as easily or as effectively alone. The Project Incubator supports this process. The Project Incubator creates a process that allows us to propose, review, select, and then work on great ideas together! **We have initiated, approved, and completed 7 of 7 projects since our founding in 2013 using this process!**

You will have the opportunity to evaluate the most recent project idea via a SurveyMonkey instrument. We will ask if you think CAC2 should organize a Think Tank team to develop a Working Paper identifying both the potential ethical issues charities face when funding research, as well as the Best Management Practices (BMPs) charities use in dealing with those issues. The Working Paper would be shared with CAC2 membership as a tool, could be presented by CAC2 at medical conferences as appropriate, and would be a "living document" that would be maintained and updated by the project team.

**This description provides background information to help you evaluate the proposed project and gives you the opportunity to ask questions or make clarifying observations.**

Participating in the Project Endorsement Process is one of the most important things you can do as a CAC2 member! Thank you, in advance, for your participation.

## **What is the Project under Consideration?**

### **“CAC2 Think Tank: Exploring the Potential Ethical Issues & Best Management Practices for Childhood Cancer Charities Funding Research”**

The project team believes that CAC2 has an opportunity to be a “thought leader” in the area of potential ethical issues charities face when funding research. The project team believes that in today's challenging times, and with childhood cancer kids and families facing the most difficult time of their lives, it's more important than ever to make sure our charities present themselves and follow practices when funding research in a manner that meets the highest ethical standards.

The project team would organize a “think tank” team to develop a Working Paper identifying both the potential ethical issues charities face when funding research, as well as the Best Management Practices (BMPs) charities use in dealing with those issues. The Working Paper would be shared with CAC2 membership as a tool, could be presented by CAC2 at medical conferences as appropriate, and be a “living document” that would be maintained and updated by the team.

After a preliminary investigation by the project team, it became apparent that there is little currently published information in this area. The goal of the think tank is to produce a Working Paper, providing a novel contribution to literature on this issue. The publication will add to the dialogue about the issue but would not conclude and/or create rules/regulations regarding the issue. The think tank team would work in collaboration with one or two content experts in the medical ethics field for additional perspective. Prior to submitting the paper for publication, the think tank team will present the findings to CAC2 members.

A key element of the project will be an audit of existing practices in pediatric rare disease, adult disease specific, and medical professional organizations to assess current trends in ethical standards guiding interactions between the funding organizations, donors, and recipient organizations

## What are the Steps to Complete the Project?

1. Identify interested individuals/organizations who want to contribute to this project (all CAC2 members are invited to participate).
2. Identify an ethics advisor(s) familiar with potential areas of concern and enlist as an authority to oversee.
3. Identify and consult with rare disease group(s) for existing templates.
4. Identify all elements to be addressed (including):
  - confidentiality of patient information
  - confidentiality of research data
  - disclosures of interests
  - conflicts of interest such as accepting money from pharmaceutical companies <sup>[1][2]</sup>
  - relations and advocacy roles affecting pharmaceutical companies
  - serving in government advisory roles
  - transparency in support for research
  - transparency in family support (i.e. pass through funding)
  - conduct on social media
  - accurate use of statistics and data in appeals for donations
  - fundraising tactics and claims for “cures”
  - scientific review processes
5. With the guidance of the Ethics Advisor, divide the topics into logical groups.
6. Research common practices.
7. Produce draft(s) to describe the issues and identify best practices in response and/or brainstorm novel solutions to address the issues.

8. Edit and produce final draft for submission for publication.
9. Recommend areas of future exploration for other CAC2 Pillars where issues of ethical nature might be applicable.

### **What Are Members' Roles or Opportunities?**

- Members are invited to serve on the think tank teams to investigate and create the Working Paper.
- Members are invited to attend a presentation/webinar of the findings.

### **What Will This Cost?**

There is no cost involved with this project. The key resources are CAC2 members' time commitment and the voluntary participation of one or more Ethics Advisor.

### **What is the Benefit to CAC2 Members?**

The Working Paper can help guide the discussion by childhood cancer organizations in their interactions with researchers, other charities, families, and pharmaceutical companies, as well as in their social media campaigns.

### **What is the Benefit to the CAC2 Organization?**

By publishing a working paper in the area of childhood cancer funding and researcher relationships, it will demonstrate continued leadership and enhance the credibility of CAC2 in the field.

Upon establishment of this project, this idea could be expanded upon further to touch other CAC2 pillars. For example, this model might also be applied to Family Support and Advocacy as they consider ethical issues that specifically affect their respective areas.

Finally, while CAC2 has been successful in the first 5 years by creating tangible results for the childhood cancer field (i.e., Bench to Bedside Research conference, HOPE Portal, Advocacy efforts, etc.), a 'think tank' type of endeavor has not yet been attempted. Establishing CAC2 as a thought leader in the childhood cancer arena is an important next step in order to more substantially cement the credibility of the organization in the childhood

cancer landscape. This project would be a feasibility study to understand the best way to engage CAC2 members and to produce publication-worthy content as a childhood cancer think tank.

### **What are the Benefits to the Larger Childhood Cancer Community?**

Based on our belief that there have been no publications on ethical issues for any charities funding medical research, our hope is that the Working Paper could also be leveraged as a presentation or poster at scientific meetings, and stimulate discussions beyond the pediatric cancer field.

In addition, establishing this topic as an area of interest will hopefully attract others to dialogue about potential ethical issues, which might arise and thereby generate further exploration by other entities to establish “best practices” in the area.

This type of publication might also be helpful for new philanthropies as they embark on their respective journeys as well as existing philanthropies in areas outside of the CAC2 pillars, i.e., Financial Policies, etc.

Finally, the publication would be in alignment with CAC2’s aspirations to create a legacy of thoughtful perspective on a wide array of issues that are childhood-cancer centric.

### **Does this Project duplicate other efforts within the community?**

There has not been a study of this kind published in the pediatric cancer space, nor in other disease spaces. By engaging in a project of this sort, it will demonstrate continued leadership and enhance the credibility of CAC2 in the field.

**Please note -- the purpose is not to establish specific rules/regulations or enforce any of the same; but rather to generate thoughtful discussion and consensus about the issues that pose potential ethical questions in the relationships between the funding agencies and the researcher/medical recipients.**

Once again, later this week you will receive a link to a survey through SurveyMonkey and you will be asked to evaluate this project idea by voting for

or against the project. **The survey will take NO MORE than 5 minutes** to complete and you will be asked:

- Are you in favor of CAC2 creating a think tank to study and create a Working Paper exploring the ethical issues faced by childhood cancer organizations that fund research?
- If yes, do you have further comments or suggestions to make this project a greater success?
- If no, do you have further comments about your reservations?
- Would you or your organization support the project by:
  - Volunteering to serve in a project volunteer role?
  - Providing input, if asked, about your organization's practices?

Your input is of great importance to us and we thank you, in advance for reading this document until the end. **If you have questions or need more information, you may email or phone:**

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<sup>[1]</sup>[https://www.google.com/url?q=http://www.socialworker.com/nonprofit/ethics/ethics-in-fundraising-book-excerpt/&sa=D&ust=1532628959563000&usg=AFQjCNGmSF7c\\_6FoooTOMTG1kNGSYIxPQA](https://www.google.com/url?q=http://www.socialworker.com/nonprofit/ethics/ethics-in-fundraising-book-excerpt/&sa=D&ust=1532628959563000&usg=AFQjCNGmSF7c_6FoooTOMTG1kNGSYIxPQA)

<sup>[2]</sup><https://www.philanthropy.com/article/How-Health-Nonprofits-Handle/160015>