



Better Together: Survivorship Connection

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Agenda

- Survivorship Statistics and Origins of this Project
- Review Better Together Project and the 4 Phases
- Phase 1
- How Better Together Differs from the Hope Portal?
- Phase 2: Better Together: Survivorship Connection
 - What is it?
 - How Does the Personalized Approach Work?
 - Who Will be Interested In and Benefit From this Program?
 - Value of the Program
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 - What's Next?
 - What Does Done Look Like?
- Q&A
- Next Steps



"I'm really excited about the CAC2's Survivorship Interest Group's Better Together project, focused on our precious survivorship community. Survivorship is the objective! And even though our foundation's mission is directed at funding research and raising awareness, if done well, our mission leads to survivorship. In our connection to families with children diagnosed with a brain tumor, so many questions come up about planning for care following treatment. There is an enormous need to connect families with the best, most current and complete information as they are largely responsible to navigate it. I would be thrilled to point our families to this work knowing the research that has gone into it."

Kim MacNeill, President/Co-Founder

The Ross K. MacNeill Foundation

CAC2 Membership Lead



Survivorship Statistics



According to the **CAC2 Childhood Cancer Fact Library**:

- In 2015 there were 429,000 childhood cancer survivors in the US. This number was projected to be >1/2 million by 2020.
- More than 95% of childhood cancer survivors will have a significant health-related issue by the age of 45.
- $\frac{1}{3}$ of survivors will suffer severe or chronic late effects, $\frac{1}{3}$ of survivors will suffer moderate to severe late effects, and $\frac{1}{3}$ will suffer slight to moderate late effects.
- Cognitive impairment affects up to $\frac{1}{3}$ of childhood cancer survivors.
- 10% of childhood cancer survivors experience a secondary cancer within 30 years of their initial diagnosis.

Survivors face physical and psychosocial late effects that lead to educational, financial, employment, medical care, health insurance, and other challenges throughout their lives.

The Beginning



Better Together: Survivorship Connection was started on the foundation that we are all 'Better Together'. We want to ensure that survivors and their parents, caregivers and other family members have access to the currently available resources, programs, and services.

- *We do not want current survivors and their caregivers and families to feel alone and frustrated.*

When we work together, we CAN change the future for childhood cancer survivors, and their parents, caregivers, and other family members.



BETTER TOGETHER

Helping survivors and their families navigate the support landscape



Phase 1: Creation of a database of organizations offering services and resources for childhood and adolescent cancer survivors, caregivers, and organizations. This new database currently includes over 125 organizations.

Phase 2: Creation of a "navigator" program offering stakeholders a personalized path to locate supporting nonprofit organizations in the database. This phase is currently submitted to the Project Incubator.

Phase 3: Encourage organizations to create learning opportunities centered around survivorship services. Increase the number of survivorship organizations on the Hope Portal and the Better Together database.

Phase 4: Facilitate and promote nonprofit partnership with Momcology and Imerman Angels to develop peer support programs for survivors and caregivers.

Supporting childhood cancer survivors and their caregivers by providing them with relevant resources and services is extremely important as they deal with the challenges of survivorship. Coordinated action and collaboration are key CAC2 principles that we want to harness with this project because we truly believe we are all "Better Together."

From Page 27 of the CAC2 2020-2021 Annual Report:

<https://cac2.org/wp-content/uploads/2021/07/2021-CAC2-Annual-Report-Web.pdf>

Phase 1: Build Spreadsheet of Organizations

- Consists of organizations offering survivorship resources, programs, and services that our team members and CAC2 have previously worked, or have been extensively researched by the Better Together Working Group
- Sought input from CAC2 members and collaborated with Momcology to advertise for spreadsheet suggestions.
- Data will be a “living” document.
 - From 125 organizations to 175 organizations since the Annual Report was printed in **early September 2021!!**
 - Turn the spreadsheet into a database, if approved.
 - Identified key survivorship search categories.

How Does Better Together Differ From the Hope Portal?



Better Together Spreadsheet	Hope Portal
Organizations are added by Better Together Working Group members after experience, research, and recommendations.	Organizations must physically add their information to the Hope Portal.
Future vetting criteria will be developed.	Organizations need to fit specific vetting criteria and the current structure of the Hope Portal.
There are multiple search categories, specifying assistance with various survivorship challenges and concerns.	“Survivorship” is one category, and the assistance an organization offers is not specified.
Categories focus on childhood cancer survivorship challenges and concerns with no age limits.	Categories largely focus on concerns while in treatment for childhood cancer patients (age 0-19).
NPOs, government, and relevant organizations can be added that offer resources, as well as programs, and services.	Mostly consists of nonprofit organizations that offer programs and services, and there are few resources.

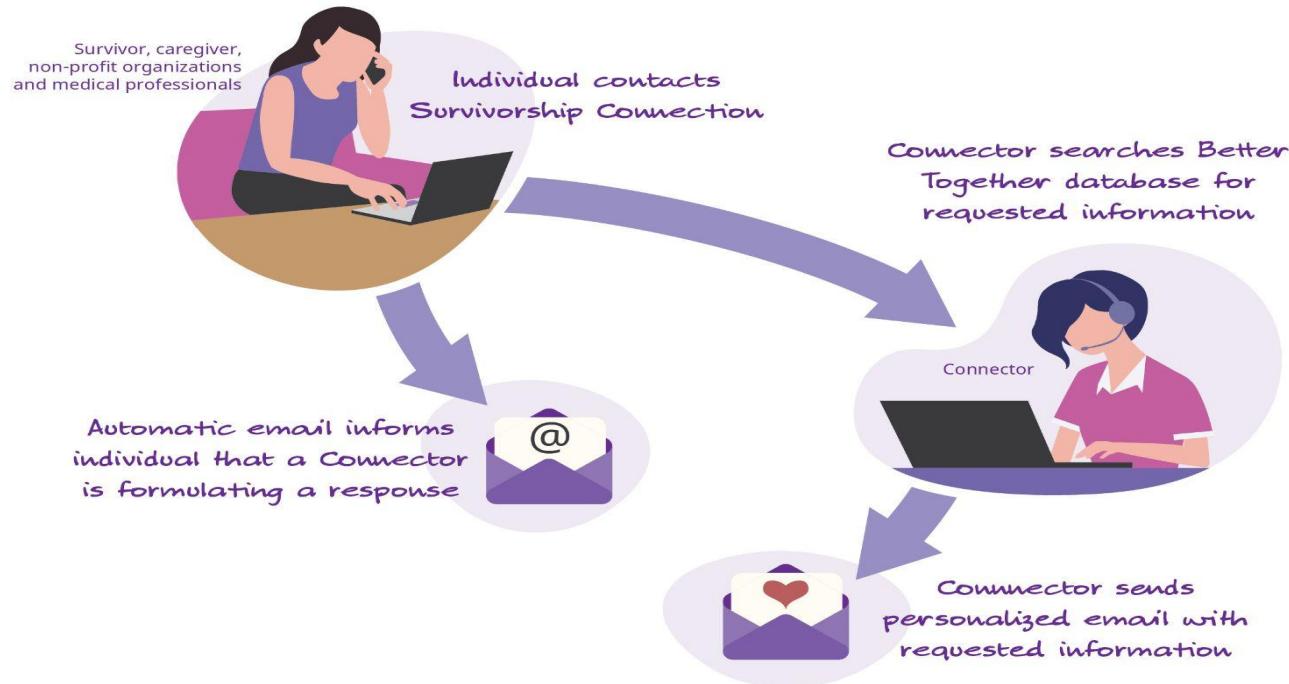
Phase 2: Better Together: Survivorship Connection

- Provides a unique connection to survivorship resources, programs, and services that address the various challenges survivors face.
- Creates a one-stop shop of organizations offering survivorship support.
- Provides a personalized approach for survivors, their family members, and other relevant stakeholders.
- Ultimately, assists in the lifelong journey of childhood cancer survivorship.



Better Together: Survivorship Connection

A personalized program connecting stakeholders with organizations providing survivorship resources, programs and services.



Survivorship Connection



Survivor finds funds, scholarships, camps, flights, etc.



Phase 2: Better Together: Survivorship Connection

Phase 2 Steps:

- Develop Connector Responsibilities and Guidelines.
- Design Training Materials.
- Find, Recruit, and Secure Connectors.
- Turn our spreadsheet into a database.
- Launch Program.
 - Soft Launch - Pilot the program to CAC2 members first?
 - Extend program beyond CAC2 for all survivors, their caregivers and families, nonprofit organizations, medical professionals, etc.

Who Will Be Interested in and Benefit from Better Together: Survivorship Connection?



- The Coalition Against Childhood Cancer
- Childhood Cancer Survivors – all ages and stages of survivorship
- Parents, Caregivers, and Families of Childhood Cancer Survivors
- Medical Professionals Working with Survivors
- CAC2 Members (individuals and organizations)
- The Organizations in the Better Together Database
- The Hope Portal

Value of this Program



- Provide a personalized service to: childhood cancer survivors; their parents, caregivers, and families; NPOs; medical professionals; and others.
- Increase visibility for CAC2 and the Hope Portal.
- Elevate survivorship as a whole.
- Recognize that CAC2 is invested in survivorship.
- Increase organizations joining the Hope Portal, and increase those using the Hope Portal.
- Increase CAC2 membership.

Sustainability of Spreadsheet/Database



- Use of Anddit and the team from KBI Biopharma, who work on the Hope Portal.
 - Similar to the new Foundation Match initiative.
- Find additional people interested in working on the spreadsheet/database.
- Update existing organizations annually.
- Continue to advertise for new organizations.
- Create vetting criteria.
- Marketing campaign.

Sustainability of Connectors



- Find, recruit, and secure Connectors.
 - Marketing campaign.
 - Advertise among CAC2 members.
 - Advertise among non-CAC2 members.
 - Personal Engagement
 - People utilizing the program may want to become a Connector.
 - Connectors may help identify new possibilities.
- Refine Connector responsibilities, guidelines, and training materials.
- Incentivize to keep Connectors.
 - Personalized “Thank You” cards.
 - Possible long-term goal - find a sponsor to provide some form of financial incentivization.

What Does Done Look Like?



Better Together: Survivorship Connection will be fully established and provide a **personalized service** for survivors and their parents, caregivers, and other family members, as well as nonprofit organizations, medical professionals, and others, **to find survivorship resources, programs, and services for their specific needs and requests.**

- Our spreadsheet will include organizations from all 50 states.
- Volunteer 'Connectors' will be onboarded, and the program will be launched.



Thank You!

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 @CoalitionAgainstChildhoodCancer

 @cac2org