



2022 CAC2 Annual Summit: Survivorship Interest Group Notes

Thank you to those that attended the Survivorship meeting at the 2022 CAC2 Annual Summit, and to those of you reading these notes! It was wonderful to speak with CAC2 members from both large and small organizations that want to incorporate survivorship into their mission and that were interested in our projects. Once completed, the Survivorship Interest Group's two projects, Better Together: Survivorship Connection and the Survivorship Toolkit, will be two resources that organizations can refer survivors and their families to directly. Furthermore, I was honored to open this meeting with the announcement that the Neuroblastoma Children's Cancer Society (NCCS) gave a \$2,500 grant to Better Together: Survivorship Connection, and a \$2,500 grant to the Survivorship Toolkit project! ***Please email me if you are aware of any other sponsorship or grant opportunities for these projects (survivorship@cac2.org).***

BETTER TOGETHER: SURVIVORSHIP CONNECTION: The number of childhood cancer survivors in the United States continues to increase, but searching for resources, programs, and services that support or address a particular survivorship need or challenge can be frustrating, time-consuming, and may result in few and ineffective results. Furthermore, survivors and their families often feel alone, isolated, and frustrated with a lack of resources and support. Better Together: Survivorship Connection proposes the creation and volunteer staffing of a personalized approach to connect childhood cancer survivors, their parents, caregivers, and other stakeholders with existing organizations and institutions that provide resources, programs, and services addressing childhood cancer survivorship needs or challenges. A short [video](#) further illustrates the need and explains the program.

The personalized approach is simple and depicted in our [infographic](#). Essentially, a survivor, family member, or another stakeholder submits a question to a "Connector." The Connector supplies focused-information, based on the Better Together spreadsheet via personal email response, with appropriate organizations and resources addressing that question. Connectors will undergo training and be held to strict standards, and we can begin the personalized approach fairly quickly we can initially use the spreadsheet. However, the spreadsheet needs to be converted into a database to make it more valuable and sustainable, which will take more time to build and perfect. We plan to use Anddit, the same technology platform utilized by the Hope Portal, and this technology *and* the labor is free and donated to CAC2!

We presented a [webinar](#) in February about the Better Together: Survivorship Connection program. In July, we are presenting our budget to the Board, which completes the Project Incubator process! Before we implement the program, we need to create: training materials and policies and procedures for Connectors; agreements for Connectors and other volunteers; and marketing materials for the program. We also need to complete some key work tasks, which include: find volunteers to fill the different roles; recruit and train Connectors; record virtual training for future Connectors; maintain Connectors and set up a sustainable, long-term program; advertise for Connectors and for the Better Together: Survivorship Connection program; create a vetting process and criteria for organizations; and convert the existing spreadsheet into a database.

Our most important task is finding volunteers to help us implement the program. ***We are looking for volunteers in a variety of areas, including: data collection and management; marketing and promotion; technology integration; Connector development and training; and serving as a connector. In an effort to discuss these volunteer roles and get to know you better, we will be holding two "meet-and-greet" virtual meetings, where you can choose the one that works best for your schedule. The first meeting is on August 2 at 12:00 p.m. ET, and the other meeting is on August 11 at 7:00 p.m. ET.*** Further details about the different volunteer opportunities and the links to register for the Zoom meetings can be seen [here](#). You can

also see the meeting details on the Better Together calendar on the Member Hub. Please email me if you have any questions about volunteering or these meetings (survivorship@cac2.org).

Attendees at this meeting were excited that this project will create efficiencies and give survivors and other stakeholders the direct information that they need and can use. There is a lack of communication about available resources for survivors, and Better Together: Survivorship Connection directly addresses this. The group also believed that this program should be used by both CAC2 and non-CAC2 members, similar to the Hope Portal. We also discussed whether the database should only be used by the Connectors, or if it should be open to the public. This is a repeated topic of conversation, and the consensus at the meeting was that the database should be open to the public, which would extend the program to even more survivors and relevant stakeholders. Some may not want to use the personal approach and would rather search themselves. If they are unable to find resources for a particular question or issue, or they want additional resources, then a survivor or relevant stakeholder can contact a Connector and use the personal approach. Concerns were raised about the sustainability of the Connectors, and maintaining the ideal number of Connectors. A hybrid approach using the personalized program and opening the database to the public would help ensure the sustainability of both the program and the Connectors. Furthermore, a pilot program would allow us to start slow, provide extra training, and ensure that everything is working effectively and efficiently.

SURVIVORSHIP TOOLKIT PROJECT: As we have learned, childhood cancer survivorship is growing but there is a void of support and little information available for survivors and their family members. Although there are some wonderful survivorship toolkits that exist, they only address a few different topics. This project would be more comprehensive and list everything all in one place. We do not want to recreate the wheel, so we will highlight the organizations who have addressed things well, but we also know that we will need to create some content. The purpose is to provide resources for survivors and their families that address some of the challenges and issues that are faced during survivorship. The Survivorship Toolkit project was introduced with a [video](#) that summarized and explained the project. In addition, a [handout](#) was distributed that listed the objectives of the Toolkit, how it will be broken down, and the audience and scope of this project. Furthermore, we have divided our original list of content into six different categories: Educational Guidance and Planning; Insurance and Financial Health; Managing Physical Health and Late Effects; Psychosocial/Emotional Health/Wellbeing; Transitioning to Adulthood; and Wellness/Healthy Behaviors. Each of these categories includes an organized list of sub-categories, or topics that we want to cover, and you can view the complete list [here](#).

Our working group decided to begin this project by working on the "Educational Guidance and Planning" category, and we have been and will continue to gather resources to address all of the education sub-categories. It is also important to note that this project is not only for survivors and their families, but medical professionals, nonprofit organizations, and other professionals working with childhood cancer survivors can benefit from the information in the Toolkit. They can also assist survivors and their families by introducing them to the CAC2 Survivorship Toolkit project. Furthermore, we also have an introduction that was written for this project by Dr. Melissa Hudson, the Director of the Survivorship Division at St. Jude.

We have been meeting monthly on the 4th Friday of the month, except for one week earlier during September and the holidays. However, attendees at the Summit expressed an interest in changing the meeting date and time, so we are investigating potential alternatives and will send out a poll shortly.

We also discussed a few new goals for the Toolkit. First, we want each category to have resources addressing the different sub-categories by Spring 2023, which will give us time to prepare for the 2023 Annual Summit. ***A simple, easy way for anyone to become involved with this project is to email resources (survivorship@cac2.org) that address any of the sub-categories, including websites, mp4s, journal articles, pdfs, professionals, and more.*** Also, to help us reach this goal, we are seeking a "Category Content Manager," which is someone to help gather a collection of resources for each category. This job does not mean that you are in charge of finding resources for every sub-category on your own! We would help identify volunteers and other connections that could contribute resources, and we would be available to assist

you along the way. Along with working on the education category, we already had two people volunteer to take on two of the remaining categories! ***Please contact me if you would be willing to take on one of the remaining categories - Insurance and Financial Health; Psychosocial/Emotional Health/Wellbeing; and Wellness/Healthy Behaviors.***

It is important for us to start working on the virtual component of this project, and identifying the best way to present the Toolkit and all of the information. The CAC2 website has the capacity to hold this project, but we will need to find someone to build it. We need the Toolkit to be user-friendly and easy to use, but we also need it to serve all age groups, including the AYA population. We need it to capture the attention of each user, and convey the contents of the landing page with brevity. We have looked into a few examples, such as [Teen Cancer America](#). ***However, we want to hear from you and learn about any website suggestions or ways to present the Toolkit and all of its resources.***

GINNY MCLEAN, PROJECT AND CAMPAIGNS OVERSIGHT: Ginny met with us to find out how campaigns and special projects can support the Survivorship Interest Group and our projects, Better Together: Survivorship Connection and the Survivorship Toolkit. In addition, we want to recruit and engage membership for webinar brainstorming and attendance, and we also want to share information outside of CAC2. Some of the ideas that we generated during our time with Ginny included: creating a hashtag; writing blog posts; building up social media posts on LinkedIn and the public CAC2 page; creating a place, like LinkedIn, to send non-profits that are not CAC2 members; and for Better Together, we could highlight what CAC2 members are doing ‘better together’ and then discuss this project. ***The goal is to have content for September posts, so please contact me if you have any ideas.***

*****Due to time, we were unable to discuss ideas about future webinar topics and CAC2 Survivorship projects. If you have any ideas, please send an email to: survivorship@cac2.org.***