



Welcome!

To the Survivorship
Special Interest Group Breakout Session

Thank you to our sponsor

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Introductions...



SURVIVORSHIP INTEREST GROUP

Mariah Forster Olson, Survivorship Lead

 **The Neuroblastoma Children's Cancer Society**
HOPE for more tomorrows for children with neuroblastoma

Survivorship is the ultimate goal when a child is diagnosed with cancer.

Survivors of childhood cancer face unique challenges.

Introduce Yourself

- Your Name
- How are you affiliated with CAC2, and what is your organization, if applicable?
 - Your State
- One sentence to explain your connection to childhood cancer



AGENDA



❖ Hope Portal
(Mariah Forster Olson)

Survivorship




Toolkit

❖ Better Together
(Carolyn Breinich, Nick Giallourakis)

❖ Survivorship Toolkit
(Mariah and Mary Beth Collins)





A collaborative network of
organizations and
individuals supporting and
serving the childhood
cancer community



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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.

Hope Portal



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Hope Portal

Connecting Childhood Cancer Families
to Support Resources faster than ever

The Hope Portal is:

- A comprehensive database of childhood cancer support service organizations (www.hope-portal.org)
- Connects patients, survivors, and their families to resources quickly
- A collaborative success model that demonstrates the power of a unified community



Hope Portal By The Numbers

- 381 organizations listed
- 44 states represented
- 34,982 visitors to the site in last year
- 10,222 outbound clicks to organizations last year

Three Opportunities to Help

- Add or Update Your Org to the Hope Portal
- Embed or Link Hope Portal on Your Website
- Become a State Liaison



Can families find you on the Hope Portal?



Andrew McDonough B+ Foundation 

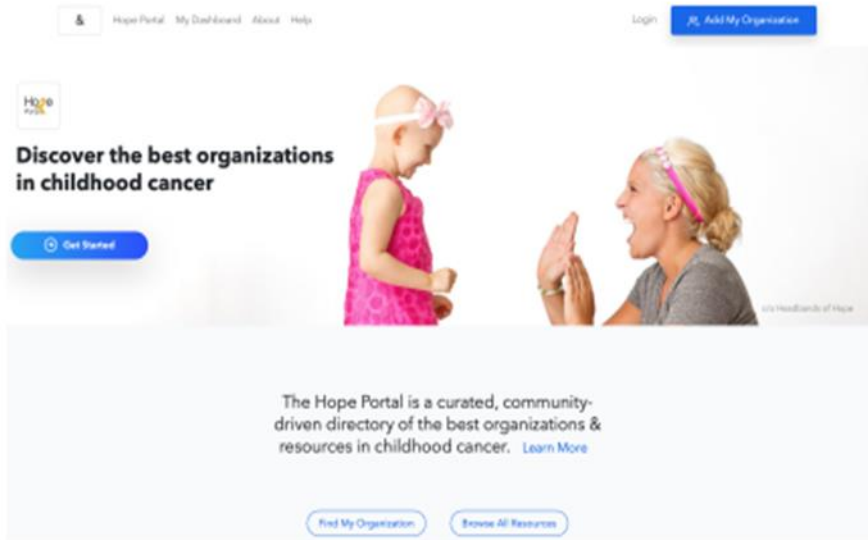
📍 Serves + All United States

The B+ Foundation is about helping kids fight cancer - by providing financial support to families of children with cancer and by funding childhood ...

 BEST KNOWN FOR
Bills

- Join the Hope Portal
- Update or claim your organization's profile

Share the Hope Portal with Your Community



- Embed the Hope Portal on your website
- Encourage other nonprofits to join
- Share with treatment center staff

Hope Portal Leadership Opportunity

State Liaisons Needed

- Connect with treatment centers in your state to raise awareness about Hope Portal as a valuable resource for their patients, survivors and families
- Connect with nonprofits in your state to encourage them to join the Hope Portal and reach more patients, survivors and families

Hope Portal Leadership Opportunity

State Liaisons Time Commitment

- Twice a year: Reach out to treatment center staff about Hope Portal
 - CAC2 will follow up with print materials
- Twice a year: Reach out to other childhood cancer charities in your state and invite them to join the Hope Portal. *There is no cost to join the Hope Portal and they don't have to be a CAC2 member.*
 - CAC2's Hope Portal vetting team will help them get set up

If you would like to help, please
contact Amy and Mariah at:

Amy Godkin
familysupport@cac2.org

Mariah Forster Olson
survivorship@cac2.org
Mariah1800@hotmail.com

Hope Portal – Expand Survivorship

- Prior to this project, 31 organizations marked “Survivorship”
 - Additional organizations that assist survivors but have not marked survivorship
 - Please mark “Survivorship” category if your organization offers programs and/or services to survivors
- Separate “Survivorship” search portion on the Hope Portal
 - New search categories (Example Ideas: Education/Scholarships; Employment; Financial/Legal; Health/Wellness; Insurance/Disability; Medical Care/Late Effects; Support Groups; Wishes/Experiences/Gifts)
- List of additional nonprofit organizations to include on the Hope Portal



Questions?



Better Together

CAC2 Connection



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Agenda

- Refresh - Goal of Program
- What We Have Accomplished
- How Will It Work?
- Next Steps – How Can You Help?!
- Q&A



Better Together: CAC2 Connection

Goal of Program

Phases of Developing the Program

- Phase 1: Build Database of Existing Organizations
- Phase 2: Launch Navigator Program
- Phase 3: Contact Organizations
- Phase 4: Partner with Momcology and Imerman Angels

Who Will This Benefit?

- Childhood and adolescent cancer survivors and their caregivers
- Organizations offering survivorship resources
- The Hope Portal
- Medical health professionals - nurses, doctors, social workers, recreation therapists, and many others

Value of the Program to CAC2

- Increase visibility for CAC2
- Increase visibility of the Hope Portal and organizations on the Hope Portal
- Increase organizations joining the Hope Portal
- Increase CAC2 membership
- Provide a personalized service to childhood and adolescent cancer survivors, their caregivers, and CAC2 member organizations requesting survivorship resources and services



Better Together: CAC2 Connection

What we have accomplished

How Will It Work?

- Our goal is that the CAC2 Connection would exist on the CAC2 Survivorship page.
- This program consists of a ‘navigator’ being available via email to assist individuals looking for survivorship resources, creating that personalized approach.
- A survivor or caregiver, or a nonprofit organization or medical professional serving this population, would submit a question regarding a survivorship concern(s), (i.e. camps or outdoor adventures, support groups, college scholarships for survivors, etc.).
- Then, within a defined period of time, the trained navigator would search our database to find organizations that fit their specific need or concern.

How You Can Help!

- Are you interested in helping us continue to build and maintain our database?
- Email us any organizations you are aware of that serve childhood cancer survivors and their caregivers.
- Do you have experience or an interest in becoming a navigator?
- Would you be able to help us create training materials and/or writing policies and procedures?

Email survivorship@cac2.org with feedback!



Thank You!

cac2.org

 @CoalitionAgainstChildhoodCancer

 @cac2org

SURVIVORSHIP TOOLKIT

Childhood cancer survivors face an array of challenges throughout their lives. There are also a number of different populations that we can address. We want to help in all these areas, but we need to start by addressing one area to provide meaningful support.



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What type of content should be included in the Survivorship Toolkit?



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How often would you like to meet to discuss the Survivorship Toolkit, and other Survivorship Interest Group initiatives?



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ANY
QUESTIONS?



The background features a vibrant, abstract watercolor design. It includes horizontal brushstrokes in shades of pink, orange, yellow, teal, and light blue. There are also scattered dark blue dots at the top and grey speckles in the middle-right area. The overall style is artistic and colorful.

wrap-up

Out of the projects presented today (the Hope Portal, Better Together, and the Survivorship Toolkit), which would you or your organization be interested in assisting with in some capacity?



Please fill out the survey, and feel free to select more than option!



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Thank You!

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