

2025 Childhood Cancer Survivor Study Education Committee Update

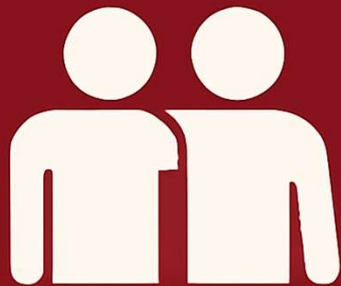
Kayla L. Foster, MD, MPH

CCSS
Childhood Cancer
Survivor Study

Baylor College of Medicine

Education Committee Objectives

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ENCOURAGE



EMPOWER



ENGAGE



EDUCATE

Education Committee Leadership Update

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Melissa M. Hudson, MD
CCSS Education Chair 1999-2024



Kayla L. Foster, MD, MPH
CCSS Education Chair 2024-Present

Education Committee Membership

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Ellen Chang, MD, MS

Casey DeBias, MSN, APRN

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Linda Rivard, RN, BSN

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Omar Shakeel, MD

Julia Stepenske, RN, BSN

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St. Jude Coordinating Center Support

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St. Jude Strategic Communication, Education and Outreach

Medical Content Outreach and Digital Integration Teams

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LTFU Newsletter

CCSS

Three newsletters annually (Winter, Summer, Fall)

Fully digital publication

Distributed to 17,000+

Newsletter Format:

- Highlight recent clinically relevant CCSS publication
- Provide survivor focused education about the topic
- Engage survivors to share their lived experience with peers
- Connect readers with resources when possible

2024-2025 Newsletter Content

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Advancing Survivors Knowledge (ASK Study) of Skin Cancer Surveillance After Childhood Cancer: A Randomized Controlled Trial in the Childhood Cancer Survivor Study

Alan C. Geffer¹, Adina Coroiu¹, Robyn R. Keske¹, Sebastien Haneuse², Jessica A. Davine¹, Karen M. Emmons¹, Casey L. Daniel¹, Todd M. Gibson², Aaron J. McDonald⁴, Leslie L. Robinson⁴, Anyi C. Mertens³, Elena B. Elkin⁴, Ashfaq Marghoob⁷, Gregory T. Armstrong⁸



Health Insurance Navigation Tools Intervention: A Pilot Trial Within the Childhood Cancer Survivor Study

Elyse R. Park¹, Anne C. Kirchhoff², Karen Donelan¹, Giselle K. Perez¹, Aaron McDonald³, Cayley C. Bliss¹, Allyson Foor¹, Karely M. van Thiel Berghuijs², Austin R. Waters², Natalie Durieux¹, Wendy Leisenring⁴, Gregory T. Armstrong³, Colin Ponzani¹, Ana Lopez¹, Perla L. Vaca Lopez², Tracy Battaglia⁵, Alison A. Galbraith³, Karen A. Kuhlthau¹



Characterization of chronic pain, pain interference, and daily pain experiences in adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study

Nicole M. Alberts^{1,2}, Wendy Leisenring³, Jillian Whitton³, Kayla Stratton³, Lindsay Abb⁴, Jessica Flynn¹, Alex Pizzo², Tara M. Brinkman¹, Kathryn Birnie⁵, Todd M. Gibson^{1,6}, Aaron McDonald¹, James Ford¹, Jeffrey E. Olin⁷, Paul C. Nathan⁷, Jennifer N. Stinson⁴, Gregory T. Armstrong¹

Sample Newsletter Content

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Survivor does not let chronic pain stop her



Survivor Rachael Bull is working on her PhD in biomedical science.

When Rachael Bull was 6 years old, she was diagnosed with a tumor called [rhabdomyosarcoma](#). Her cancer had spread throughout her abdomen (belly).

Because the cancer had advanced, Bull received radiation to her whole abdomen. Bull, now 22, still has health problems from the [radiation](#) and [chemotherapy](#) she received. Bull has dealt with chronic pain throughout the 20 years since her treatment.

Today she is working as a forensic anthropologist.

She has lower back pain, and it is a challenge to pursue her PhD.

It is hard to know how to manage her pain, and often she feels overwhelmed.

Pain is an

Texas survivor talks about her approach to skin health

When Maren Davis, 22, was 3 years old, she was diagnosed with a brain tumor. Because she was so young, she has few memories of that time in her life.

She had surgery and 6 weeks of radiation to her head and neck area. That was followed by chemotherapy with stem cell rescue. Stem cell rescue replaces blood stem cells destroyed by chemotherapy. Davis stayed cancer-free until she was 6.

Unlike her first experience with cancer, Davis clearly remembers finding out she had skin cancer in 2007. A mole on her left cheek had lightened in color so that it had a translucent appearance. Davis' mom took her to the doctor. A mole that changes in appearance can be a symptom of skin cancer. The mole was also in an area where she had received radiation for her previous cancer.

A doctor removed the mole and sent it for testing. When it was looked at under a microscope, it showed signs of cancer. The mole turned out to be melanoma, the most aggressive form of skin cancer.

Ribulotta encourages fellow survivors to advocate for themselves

As a childhood cancer survivor, Martin Ribulotta, 31, has more doctor appointments than the average person in their 30s.

He was diagnosed with astrocytoma, a brain tumor, as an infant. He had surgery and chemotherapy at Children's National Hospital in Washington, D.C. The cancer came back twice and was treated with surgery both times. Ribulotta has been cancer-free since 2001.

After his treatment, these are called late effects, and they are slightly shorter than his left.

Ribulotta is glad he has health insurance to cover most of his medical expenses. But making sense of the health insurance system can be quite challenging, he says. That is why he took part in the .TFU study aimed at helping childhood cancer survivors increase their health insurance knowledge and understanding.

Before the study, Ribulotta describe his level of health insurance knowledge as "basic." The study helped shed some light on the matter.

Health insurance in the United States truly requires ongoing and constant education," Ribulotta says.



Ribulotta during treatment for astrocytoma when he was a baby.



Maren Davis pays close attention to her skin health after having skin cancer. She has been cancer free since 2009.

"The newsletter made it feel like I was part of a community, even though I just flipped through it sometimes."

What we have learned ...

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- Newsletter is a key source for information for participants
- Desire information on study results
- Newsletter made them feel less alone in their health struggles, sense of community
- Critical for study retention
- Opportunities: desire for more newsletters and alternate media sources (social media); focus on research results and experiences of other survivors like them

Future Directions

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- Actively seeking newsletter specific feedback from participants noting the newsletter as having a positive impact on their engagement in the study through focused survey
 - Potential for focus group or more detailed survey pending engagement
- Seeking new topic/format ideas to incorporate high-value topics for survivors that may not be the focus of active CCSS investigation
- Focus on improving representation across race, ethnicity, gender, sex and treatment exposures for survivor spotlights and expert engagement
- Considering ways to leverage this content for broader dissemination and accessibility

Check out our content

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Newsletter



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Summaries**