



## News & Updates

September 2022 | Volume 13 - Number 8

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Spreading Hope Through Psychosocial Support <sup>SM</sup>

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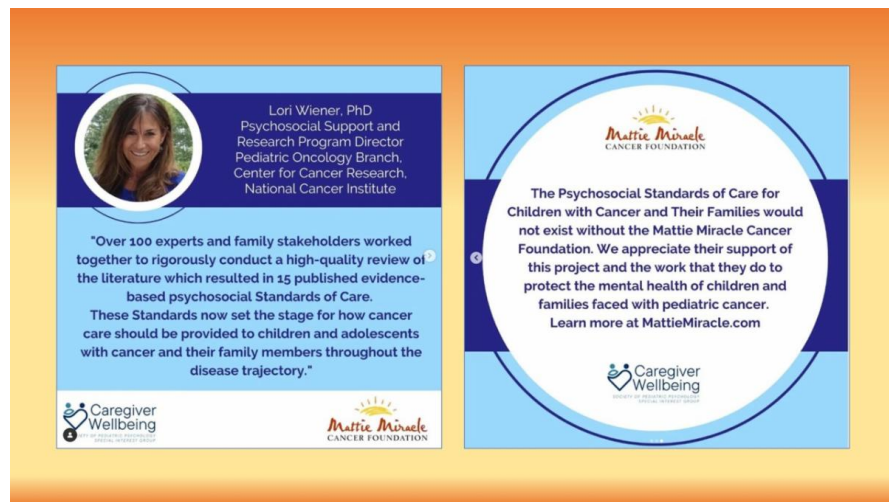
### Support

Help Make The Miracles Possible

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## Partnership for Awareness

September is childhood cancer awareness month. We acknowledge all the courageous children and their families affected by this disease. Around 46 children a day are diagnosed with cancer and seven children a day die from cancer in the United States (Surveillance Epidemiology and End Results Cancer Statistics Review/ National Cancer Institute, 2012).

Mattie Miracle is honored to **partner with the American Psychological Association's Division 54 - [Caregiver Wellbeing Special Interest Group](#)** to launch a social media campaign about the importance of psychosocial care and the evidence-based Standards guiding this support. A special thank you to [Dr. Chrissy Salley](#) (co-chair of the special interest group), [Dr. Lori Wiener](#) (co-director of the behavioral health core, NCI), and Allie Neenan (clinical psychology doctoral student) for their efforts to make this campaign a success.

The Caregiver Wellbeing Special Interest Group understands that a child's cancer diagnosis and treatment can impact the mental and physical health of parents, which can ultimately affect the child's treatment outcomes. Our goal this month is to spread awareness that optimal cancer treatment requires a comprehensive approach that addresses both the medical and psychosocial aspects of care.

We invite you to check out our [Instagram](#), [Twitter](#), and [Facebook](#) campaign.

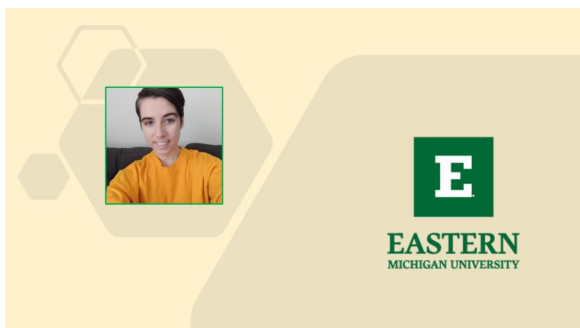
It's not just about  
the medicine!<sup>SM</sup>



## Spreading Hope Through Psychosocial Support. <sup>SM</sup>

### Did you know?

1. The **Psychosocial Standards of Care** provide evidence-based information on the emotional and social support needed to optimize the quality of life for children with cancer and their families (Wiener et al., 2015).
2. Optimal cancer treatment **must include psychosocial care** (Institute of Medicine, 2008).
3. Depression and other psychosocial concerns can affect **adherence to treatment** (Institute of Medicine, 2008).
4. Psychosocial care has been shown to yield **better management of pain and fatigue** (Jacobsen et al., 2012).
5. **Treating the pain, symptoms, and stress** of cancer enhances quality of life and is as important as treating the disease (Institute of Medicine, 2015).
6. **Siblings** of children with cancer are at risk for developing anxiety, depression, and post-traumatic stress disorder (Alderfer et al., 2003).
7. Childhood cancer survivors reported medication use for **anxiety and depression** at rates nearly two times those reported by the general public (Hawkins et al., 2017).
8. Symptoms of **post-traumatic stress disorder** are well documented for parents whose children have completed cancer treatment (Kazak et al., 2004).
9. **Financial hardship** during childhood cancer treatment negatively impacts family well-being (Bona et al., 2014).
10. The **death of a child** to cancer frequently results in depression, anxiety, loss of appetite, sleep disturbances, and fatigue (Alam et al., 2012).



### Standards Inspire Advocacy

This summer, Mattie Miracle was contacted by Alexandra (Allie) Neenan, a doctoral student at Eastern Michigan University. Allie expressed her thanks for the creation of the Psychosocial Standards of Care and discussed her interest in promoting the Standards through a social media campaign during Childhood Cancer Awareness month.

Allie designed visually appealing Instagram graphics and messages to educate the advocacy community about the 15 evidence-based Standards of Care. We are grateful for Allie's creativity, advocacy skills, and initiative to spread the message that childhood cancer is NOT just about the medicine.

I am about to enter the fifth year of my doctoral program studying Clinical Psychology at Eastern Michigan University. During this time, my research interests have largely focused on understanding how individuals impacted by childhood cancer find community and support among others going through the same thing. The Psychosocial Standards of Care, which were published while I was an undergraduate, **played a major role in my decision to pursue a PhD in Psychology** for the purpose of helping children with cancer.

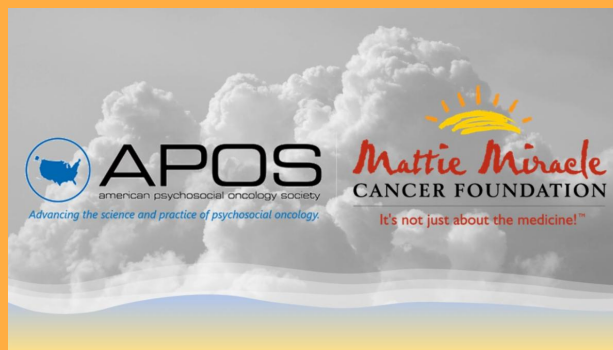
While I had always wanted to study psychology, childhood cancer is a cause that I only became familiar with near the end of my time in college. As I approached my senior year, I knew that I wanted to find a way to combine my passion for psychology with my desire to help families affected by pediatric cancer. I remember feeling confused, even thinking, “children going through cancer don’t need therapy, they need better medicine.” I cringe when I look back on this mindset, **but the truth is that many people overlook how vital psychosocial care is for children with cancer and their families.**

When I learned about the Psychosocial Standards of Care, I quickly realized just how wrong I was. **The Standards are unique in how thoroughly they address the needs of children with cancer and their families.** These documents clearly describe the research on the psychological toll of cancer and they set the stage for why comprehensive care is so important. The Standards describe over a dozen ways that every single medical center that treats children with cancer should be working to address their psychosocial needs. The Standards helped me to understand **that psychologists have the power to buffer the harm of nearly every aspect of the cancer experience - from communicating about the diagnosis, to supporting children through medical procedures, through adjusting to life in survivorship or bereavement.** I went from wishing I had chosen a degree that could lead to a career helping children with cancer to realizing that the options were truly endless. Sadly, these options represent the myriad harms that children with cancer go through every day. This September, I am grateful for foundations like Mattie Miracle and the work they do to minimize the suffering caused by childhood cancer.



## Our Partnership

In 2013, Mattie Miracle held its first Psychosocial Think Tank at the American Psychosocial Oncology Society (APOS) annual conference in Huntington Beach, CA. That event launched our long-term collaboration with APOS. We consider APOS to be our professional and research home.



APOS is the only multidisciplinary organization in the United States dedicated to researching and treating the psychosocial aspects of cancer. APOS is committed to our vision of the implementation of the Psychosocial Standards of Care at treatment sites around the country and to help achieve this goal we are honored to house our early career psychosocial research grants at APOS.

In honor of September being Childhood Cancer Awareness month, we have officially become APOS' first community partner, We view this decision as a positive step that further unites healthcare professionals and advocates together on a common cause.

On behalf of the APOS Board of Directors, we are thrilled to announce Mattie Miracle as **our first Honorary Community Partner!** We are so grateful for your continued support and significant contributions and look forward to continuing our relationship for many years to come

Thank you for your longstanding commitment to the mission, vision, and values of APOS. We are so honored to extend this first honorary community partner to you and the Mattie Miracle Cancer Foundation.

It is through continued great partnering with advocates such as the co-founders of Mattie Miracle that we will continue to make a difference! We are truly grateful that you have chosen APOS as your partner organization and for all the work you continue to do to honor the importance of psychosocial/psychological care for patients and their families.

May there continue to be great meaning in our shared work and the long legacy of Mattie and Jimmie Holland.

Share your  
story



## Giving Fathers a Voice

**Dr. Christine Denhup** is a registered nurse, and a nursing professor in the Egan School of Nursing & Health Studies at Fairfield University in Connecticut. She is conducting a research study titled "Fathers lived experience of parental bereavement after the death of a child." She is **inviting bereaved fathers to participate** in part of this study.

Cancer continues to be the leading cause of death by disease in children. In fact, on average, **five children a day die from cancer in the United States** (Siegel et al., 2021). This leaves parents to face the unimaginable, to question their identity, meaning, purpose, and future.

Dr. Denhup recently published an article which highlights the reflections of six parents whose children died from cancer. The overwhelming theme she found was **no matter how much time passes, parents never forget their children, and furthermore instead they find ways to continue the relationship and connection despite their children's physical absence**. Or as these bereaved parents would say, they "parent **Beyond the Veil**."

Click on Learn More for information on how to volunteer for the Fathers Lived Experience study.

[Learn More](#)

## Get Involved



Candy &  
Snack  
Drive

Mattie Miracle is requesting your help! Please donate candy and other snack items, so that we can continue to stock our free Snack and Item Carts at hospitals. **Our four Carts** are considered a life saver by families who are caring for a child with cancer or other life threatening illness. Our hospital Carts service **2,500 families a year**.

After a decade of successful in-person Candy Drives, we have made the difficult decision to transition to an all-virtual event. Hospitals have requested that candy remain in its vacuum sealed bags, with its manufacturer's expiration date. Therefore, the safest way to meet these requirements is to use an Amazon Item Wish List.

**You can participate in our 12th annual Candy and Item drive from anywhere in the USA.** Please view our Amazon wish list, We ask that all items be received by **November 14, 2022**.



Mattie Miracle Cancer Foundation  
[www.mattiemiracle.com](http://www.mattiemiracle.com)



Mattie Miracle Cancer Foundation  
is a GuideStar PLATINUM  
Participant Charity

