

*The National Academies of*  
SCIENCES • ENGINEERING • MEDICINE

*Board on Health Care Services*

**Committee on Childhood Cancers and Disability**

**Public Meeting Agenda**

January 21, 2020

Keck Center of the National Academies, Room 101

500 Fifth Street, NW

Washington, DC 20001

**9:30 a.m.—4:30 p.m.**

- 9:30 a.m. **Welcome and Introductions**  
*Paul Volberding, M.D., Committee Chair*
- 9:40 a.m. **Psychosocial Functioning**  
*Christopher J. Recklitis, Ph.D., M.P.H., Perini Family Survivors' Center, Dana-Farber Cancer Institute*
- 10:40 a.m. **Break**
- 10:55 a.m. **Neurocognitive Functioning**  
*Kristina K. Hardy, Ph.D., Division of Neuropsychology, Children's National Health System*
- 11:55 a.m. **Adjourn Public Session**
- 12:00 p.m. **Committee Working Lunch**  
*SSA staff, speakers, and members of the public are invited to purchase their lunches in the Keck Center Cafeteria located on the third floor.*
- 1:00 p.m. **Resume Public Session**
- 1:00 p.m. **Physical Functioning**  
*Kirsten K. Ness, PT, Ph.D., FAPTA, Department of Epidemiology and Cancer Control, St. Jude Children's Research Hospital*
- 2:00 p.m. **Functioning in Children During and Following Cancer Treatment**  
*Lisl Schweers, LCSW, OSW-C, Cancer and Blood Disease Institute, Children's Hospital Los Angeles*
- 3:00 p.m. **Break**
- 3:10 p.m. **Panel Discussion: Functioning in Pediatric Cancer Patients and Survivors**  
*Moderator: Barbara L. Jones, Ph.D., MSW, Committee Member*
- *Victoria Sardi-Brown, Ph.D., LPC, Mattie Miracle Cancer Foundation*
  - *Megan P. Elam, Ed.D., Center for School Services and Educational Research, Cancer and Blood Diseases Institute, Cincinnati Children's Hospital Medical Center*
  - *Stacia Wagner, MSW, Children's Brain Tumor Foundation*
  - *Gregory J. Aune, M.D., Ph.D., Greehey Children's Cancer Research Institute, University of Texas Health Science Center San Antonio*
- 4:25 p.m. **Closing Remarks**  
*Paul Volberding, Committee Chair*
- 4:30 p.m. **Adjourn Public Session**



# FUNCTIONING WITH PEDIATRIC CANCER: MATTIE BROWN'S JOURNEY WITH OSTEOSARCOMA

**Victoria Sardi-Brown, Ph.D., LPC**  
CO-FOUNDER & PRESIDENT

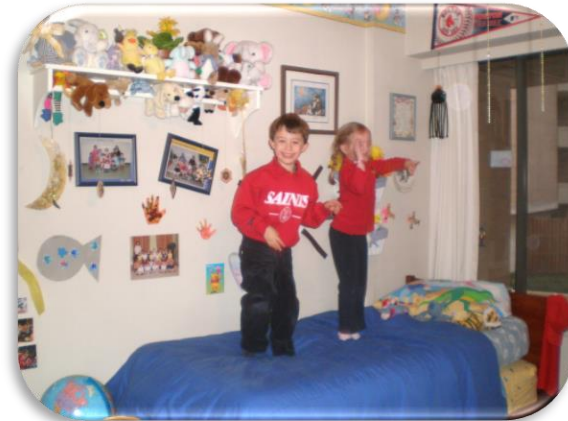


Committee on Childhood Cancers & Disability  
Public Meeting  
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# Who was Mattie Brown



- ❑ Mattie was my son and only child.
- ❑ He was a healthy, active, bright, and curious child until July 23, 2008.
- ❑ Mattie was diagnosed at age 6 with Multifocal Synchronous Osteosarcoma, Bone Cancer.
- ❑ He had four bone tumor sites at diagnosis:  
1) right arm (humerus), 2) left arm (humerus), 3) right leg (femur), and 4) left wrist (radius).
- ❑ Mattie had two limb salvaging surgeries, a sternotomy (metastasis to lungs), 10 months of high dosage chemotherapy (Doxorubicin, Cisplatin, Methotrexate, Ifosfamide, and Etoposide), experimental treatment (MTP-PE), and radiation.
- ❑ Mattie was diagnosed with clinical depression, anxiety, and medical traumatic stress.
- ❑ 14 months after diagnosis, Mattie died on September 8, 2009.





# Physical Impairments



**Limited Range of Motion**



**Unable to Walk or Run**



**One limb fully functioning**



**Limited mobility**

- ☐ Unable to walk, dress, feed, and toilet himself
- ☐ Needed wheelchair or to be carried
- ☐ Pain medication was a daily necessity
- ☐ Required hospital bed in home, commode, IV poles, and disabled placard for car

## **Long term Consequences:**

- ☐ Frustration – being dependent; difficulty relating to peers
- ☐ Isolation – unable to attend school
- ☐ Fear – did not want to be left alone; one of us always slept in the same room with Mattie
- ☐ Regression – tantrums and baby talk
- ☐ Family consequences – gave up work; back issues from lifting wheelchair and Mattie; home was transformed into a hospital; impact on all relationships



**Needed assistance**

# Psychosocial Impairments

**Exhaustion**



**Sadness**

**Isolation**



**Pain**



- ❑ These impairments maybe more discrete than the physical ones, but they were equally disabling and impacted adherence to treatment!!!
- ❑ Volatile emotions (e.g., kicking, "hate you")
- ❑ Traumatized (preferred isolation... no noise, no visitors; e.g., text message communication only)
- ❑ Constant bone pain caused agitation, fear, and hopelessness
- ❑ Trusted only us and wanted us present 24/7
- ❑ Anger – hated being different, thought he was ugly, and felt friends did not like him

## Long term Consequences:

- ❑ Diagnosed with Medical Traumatic Stress, Anxiety, and Clinical Depression; prescribed psychotropic meds (Klonopin and Celexa)
- ❑ Preferred Isolation and pushed others away
- ❑ Hyper alert and agitated (didn't sleep, nightmares, didn't want to be touched)
- ❑ Family consequences – exhaustion, fear, depression, impact on all relationships ; full time caregiver, nurse, friend, and mom to Mattie



**Traumatized**



**Depressed**



**Anger**

# Mattie Miracle Cancer Foundation

A 501(c)(3) tax-exempt public charity dedicated to PSYCHOSOCIAL awareness, advocacy, support, and research of childhood cancer.

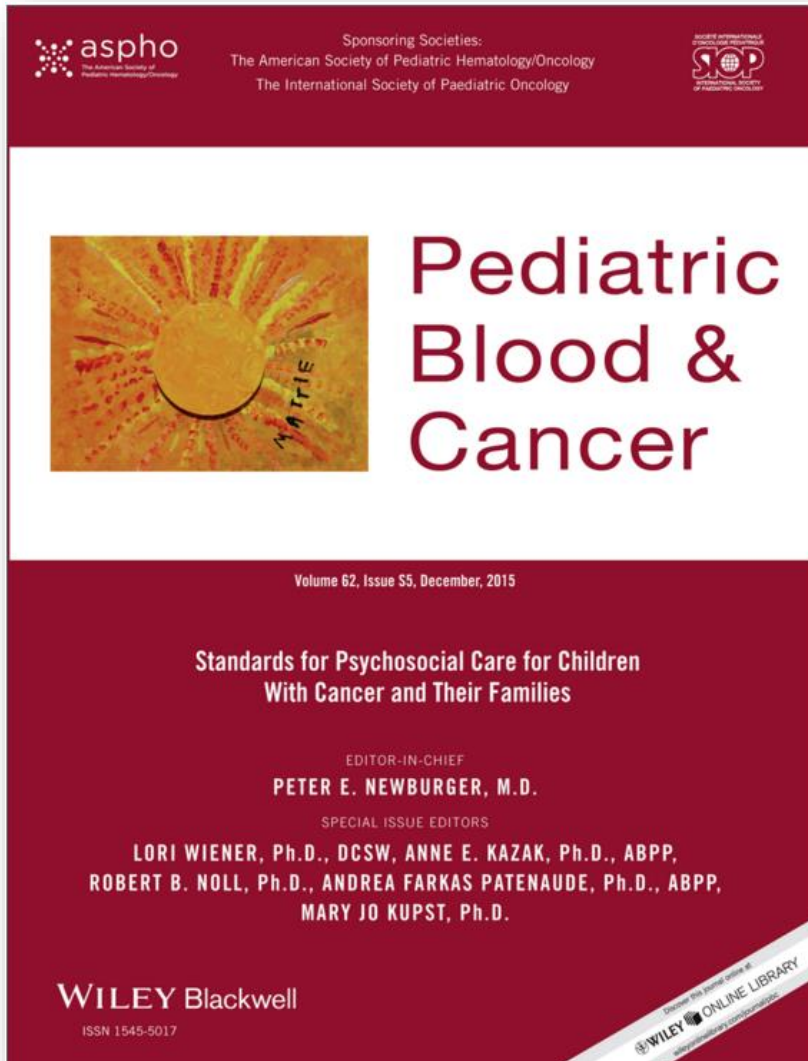
With childhood cancer we believe that.....

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

**Psychosocial providers play a vital role in assessing and treating the functional impairments experienced by children with cancer and their families.**



# Standards Published in December 2015



**16 papers; 66 authors; 1,217 studies**

- ❑ Our vision was to create the Psychosocial Standards of Care for Children with Cancer and Their Families.
- ❑ If these Standards were operationalized when Mattie was treated, I believe his psychosocial impairments would have been less severe, better managed, and would have enhanced his quality of life.
- ❑ As parents, the Standards would have given us access to evidence-based support. Mattie's impairments affected our daily lives and have long term consequences on our own health and psychosocial well-being.