For Immediate Release:  
March 18, 2014  

NCCN 19th Annual Conference Opening Roundtable:  
Communication is Key for Children of Parents with Cancer

NCCN’s opening roundtable focused on the child’s experience when a parent has cancer, noting that honest, age-appropriate communication about cancer, its treatment, and death are beneficial at any age.

FORT WASHINGTON, PA — On March 13, 2014, The National Comprehensive Cancer Network® (NCCN®) opened its 19th Annual Conference: Advancing the Standard of Cancer Care™ with a roundtable discussion titled, The Child’s Experience When a Parent has Cancer. The panel, moderated by Lillie D. Shockney, RN, BS, MAS, The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, explored recommended communication strategies for parents and clinicians to ensure that a child is appropriately prepared when a parent is diagnosed with cancer.

The panelists for this year’s opening roundtable were Martha Aschenbrenner, MA, The University of Texas MD Anderson Cancer Center; Bruce Ham, Single Fathers Due to Cancer Support Group, UNC Lineberger Comprehensive Cancer Center, and author, Laughter, Braids and Tears; Paula K. Rauch, MD, Massachusetts General Hospital; Zoraida Sambolin, Emmy Award-winning journalist and former co-anchor for CNN’s “Early Start”; and Maya Silver, co-author, My Parent has Cancer and It Really Sucks.

Ms. Shockney, Administrative Director of the Johns Hopkins Breast Center, Director of the Johns Hopkins Cancer Survivorship Program, and two-time breast cancer survivor,
described her experience of being diagnosed with cancer as a parent of a young child. Ms. Shockney described how cancer has been a routine part of life for her daughter, Laura, who was 12 years old at the time of her mother’s initial diagnosis and 15 at the second.

Ms. Shockney told the audience of a time when she had the opportunity to hear her daughter interviewed on the radio about her mother’s cancer, describing how, as a teenager, she was scared of the disease—but ultimately finding strength in her experiences.

Open, honest communication is key as a parent with cancer, agreed the panel. They expressed that parents must be honest with their children about diagnoses and, at the same time, welcoming of their thoughts, feelings, questions, and fears.

Ms. Aschenbrenner, a palliative care and rehabilitative medicine counselor specializing in raising emotionally healthy children, and cancer survivor, described the complexities of age-appropriate concepts and descriptions of cancer, its treatment, and prognoses.

“When children are forewarned, it does not raise their anxiety,” she explained. “As parents, we want to protect our children, but we also know that honesty and honest information is the best predictor of how children will cope when a parent is dying…it helps them to trust the people who are caring for them.”

When talking about cancer—and death—Dr. Rauch described how, within the Parenting at a Challenging Time (PACT) program at Massachusetts General Hospital, a child’s development level is paired with his or her temperament to determine the best approach to communicate with that child. From that point, staff works with the parents to identify other support systems within the family and in the community.
“How kids have coped with previous challenges that are much smaller actually will inform the way you can create a support system for them and how they will experience this particular challenge,” she said.

“You need to know your own kid,” said Ms. Sambolin, as she described her children’s reactions at the news of her diagnosis with breast cancer. At that time, Ms. Sambolin’s son, 14 years old, quickly created his own support system within his network of friends and proactively educated himself about the disease. He became her advocate and caretaker, she said, while, only nine at the time, her daughter asked very few questions.

“My son chose to walk the journey with me,” she said. “It taught me that kids are resilient—that kids can handle a lot more than we think they can handle—and it also taught me that when he faces adversity, he is going to step up and he is going to be able to handle it.”

The emphasis on communication stemmed far beyond her home, explained Ms. Sambolin, as she ultimately chose her care team based on their ability to communicate openly with her and her children.

“They were both great teams. They both had all the credentials,” she said. But, Ms. Sambolin explained that, her treatment team included her son and, ultimately, she chose treatment with the oncologists, nurses, and radiologists with whom they both could communicate best: “I knew that if I had difficult conversations that needed to happen, they would happen in a setting that I would feel more comfortable.”

Mr. Ham added to the discussion of the need for more communication from the clinician side of the cancer equation. A single father following his wife’s death from metastatic colon cancer, Mr. Ham has found community in his local support group—Single Fathers Due to Cancer. He noted, however, that family preparation and communication from his
wife’s treatment team following her death would have been helpful for him and his three daughters.

“You, more than anyone, are in the position to prepare families for what could come to be,” said Mr. Ham, calling upon attending clinicians to guide and prepare families facing cancer, its treatment, survivorship, and, in some cases, death.

“How has your experience with your mother’s cancer prepared you for a life crisis?” Ms. Shockney asked Ms. Silver.

Ms. Silver, 15 years old at the time of her mother’s cancer diagnosis, described how, as an adult, she is able to identify “big” problems versus “small” problems, as well as understand, identify, and implement her personal coping mechanisms. “It’s taught me a lot about what not to do,” she said. “I’ve now learned how helpful organized communication strategies would have been.”

Ms. Shockney described how honest communication with patients does not take away hope: “We know from research that we do not take away hope by being honest with our patients—they are going to go through transitions of hope,” said Ms. Shockney.

“Even up to the point that we take our last breath—and that’s been neurologically studied—we still have hope,” she said. “[Patients] are hoping that their children do well. They are hoping that their values have been instilled in their children after they’re gone. They are hoping that their spouse is going to manage well and still be able to have a good life.”

###

**About the National Comprehensive Cancer Network**
The National Comprehensive Cancer Network® (NCCN®), a not-for-profit alliance of 25 of the world’s leading cancer centers devoted to patient care, research, and education, is dedicated to improving the quality, effectiveness, and efficiency of cancer care so that patients can live better lives. Through the leadership and expertise of clinical professionals at NCCN Member Institutions, NCCN develops resources that present valuable information to the numerous stakeholders in the health care delivery system. As the arbiter of high-quality cancer care, NCCN promotes the importance of continuous quality improvement and recognizes the significance of creating clinical practice guidelines appropriate for use by patients, clinicians, and other health care decision-makers.

The NCCN Member Institutions are: Fred and Pamela Buffett Cancer Center at The Nebraska Medical Center, Omaha, NE; City of Hope Comprehensive Cancer Center, Los Angeles, CA; Dana-Farber/Brigham and Women’s Cancer Center | Massachusetts General Hospital Cancer Center, Boston, MA; Duke Cancer Institute, Durham, NC; Fox Chase Cancer Center, Philadelphia, PA; Huntsman Cancer Institute at the University of Utah, Salt Lake City, UT; Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance, Seattle, WA; The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, Baltimore, MD; Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Chicago, IL; Mayo Clinic Cancer Center, Phoenix/Scottsdale, AZ, Jacksonville, FL, and Rochester, MN; Memorial Sloan-Kettering Cancer Center, New York, NY; Moffitt Cancer Center, Tampa, FL; The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute, Columbus, OH; Roswell Park Cancer Institute, Buffalo, NY; Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine, St. Louis, MO; St. Jude Children’s Research Hospital/The University of Tennessee Health Science Center, Memphis, TN; Stanford Cancer Institute, Stanford, CA; University of Alabama at Birmingham Comprehensive Cancer Center, Birmingham, AL; UC San Diego Moores Cancer Center, La Jolla, CA; UCSF Helen Diller Family Comprehensive Cancer Center, San Francisco, CA; University of Colorado Cancer Center, Aurora, CO; University of Michigan Comprehensive Cancer Center, Ann Arbor, MI; The University of Texas MD Anderson Cancer Center, Houston, TX; Vanderbilt-Ingram Cancer Center, Nashville, TN; and Yale Cancer Center/Smilow Cancer Hospital, New Haven, CT.

Clinicians, visit NCCN.org. Patients and caregivers, visit NCCN.org/patients.