

## NCCN Roundtable Addresses the Many Faces and Challenges of Caregivers

Of the more than 1.3 million cases of cancer diagnosed each year, studies show that at least 50% of those diagnosed will be cared for by someone in their immediate family. However, providing such intense care has a significant impact on the physical, emotional, and financial health of the caregivers themselves. Sam Donaldson, ABC news veteran and cancer survivor, recently moderated a roundtable of notable panelists at the NCCN 16th Annual Conference addressing the various challenges and roles that caregivers and their family members face as their loved ones manage the disease. A video of the roundtable is now available on NCCN.com.

Mr. Donaldson opened the discussion by asking each of the panelists to talk about their initial reactions to learning that someone they loved had cancer.

Bill Cowher, analyst on *The NFL Today* and former head coach of the Pittsburgh Steelers, described his need to be “the strong one” after learning of his wife Kaye’s diagnosis of melanoma, a role that he traditionally filled in his job as football coach and in their relationship. Mr. Cowher said he questioned how he would find the words to tell his wife about the seriousness of her cancer when he was informed of her diagnosis.

Suzanne Daulerio, daughter of the late Patricia Daulerio, a long-time employee of NCCN, talked about going into “research mode,” filling her living room with print-outs of related information she found from various Web sites.

Charlie “Chaz” Ebert recounted making the decision to marry her husband, acclaimed film critic Roger Ebert, after he told her he had a recurrence of his cancer and that he would require additional treatment that eventually left him unable to speak or eat.

Jai Pausch, the mother of 3 children under the age of 5 at the time of her husband Randy’s (acclaimed Carnegie Mellon University professor and author of *The Last Lecture*) diagnosis, discussed her anger at having the life they had planned together taken away from them and the stress of having to provide medical care for her husband while trying to maintain a normal environment for her children.

Stemming from Ms. Pausch’s comments, the issues related to how to talk to children about cancer evolved as a major theme of the discussion.

Liz Scott’s daughter, Alex Scott — founder of Alex’s Lemonade Stand Foundation — was only 9 months old when she was diagnosed with neuroblastoma. Mrs. Scott talked about the challenge of discussing the diagnosis with Alex and her siblings, noting that, “if I didn’t know how to deal with this, how could I expect them to understand?”

Jill Ellen Snow, wife of the late Tony Snow, former White House Press Secretary and journalist, expressed gratitude to her husband’s oncologist for offering to help tell her children that their father was dying. Mrs. Snow explained that providing the children with honest information became a priority given their father’s high-profile occupation; she said that the media often published inaccurate reports of his condition.

Mrs. Pausch described an emotional conversation with her oldest son in which he asked her directly whether his father was dying, and she chose to protect him rather than confirm his suspicions.

Despite years of medical training, caring for someone on a personal level also has an impact on professional caregivers.

Mary Beth Reardon, RN, MS, of H. Lee Moffitt Cancer Center & Research Institute, described caring for a friend and mentor who was diagnosed with cancer as “a turning point”; she said the experience changed how she viewed her daily interaction with patients and their families and how she became more empathetic toward the caregivers.

Samuel M. Silver, MD, PhD, of the University of Michigan Comprehensive Cancer Center, described the uneasy and humbling feeling of becoming a patient himself when he viewed his own x-ray showing he had lymphoma. Dr. Silver credited his task-oriented wife for helping him through his diagnosis and treatment.

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Despite their various situations and outcomes, all of the panel members experienced long-term stress, fear, changes in relationships, and exhaustion in the process of trying to balance caring for their loved one, family members, and themselves.

Mrs. Ebert recalled her husband's oncologist advising her to take care of herself, to rest and eat because his care was a "marathon not a sprint." Priscilla Mack also recalled how she felt "pure terror," not just fear, when she heard that husband Senator Connie Mack had melanoma.

One of the most difficult issues that confronted each of the caregivers was talking about and dealing with end-of-life decisions and issues. Mrs. Pausch noted that the caregiver is often the one put in the difficult position of having to raise end-of-life issues with the patient once the prognosis becomes negative.

Ms. Daulerio said that her family avoided any discussion of dying with her mother because they thought it would be too sad, but that by the time her mother reached the final phases of her life, she was too sick to participate in critical decisions regarding her care.

All of the panelists agreed that they expected and needed honesty from their treatment team about what was happening, but had varied opinions on the value of being given statistics on the potential effectiveness of late-stage treatment options or predictions on how long a person might live.

Mr. Cowher emphasized that he focused on maintaining quality of life for his wife and their grown children near the end of her illness. He also said that he struggled with feelings of failure in his role as decision-maker.

Mrs. Ebert summarized the panel's conclusions when she urged the audience of oncology specialists to "think about the caregiver. When you are developing guidelines for treating cancer, you have to take into account the human parts, the things that go into healing both the patient and the people who take care of that person, or, if the healing fails, then the issues that are important at that stage of life as well."

The NCCN 16th Annual Conference Caregiver Roundtable, titled "The Many Faces and Challenges of Caregivers" can be viewed in its entirety or in 8- to 15-minute segments at [NCCN.com](http://NCCN.com).

## NCCN 4<sup>th</sup> Annual Asia Scientific Congress Held in Shanghai, China

More than 1800 Chinese oncology professionals attended the NCCN 4th Annual Asia Scientific Congress in Shanghai, China, on April 9, 2011, which featured expert faculty from NCCN Member Institutions and thought leaders in cancer care from major Chinese cancer centers. "This Congress represents a paragon for the developing international standards for the treatment of patients with cancer. Expert oncologists from China and NCCN discussed the most important changes in the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for many tumor types and worked together to optimize the guidelines for the treatment of patients in China," said Dr. Thomas D'Amico, NCCN Board of Directors Chair and Director of Clinical Oncology at the Duke Cancer Institute.

Esteemed faculty included NCCN Non-Small Cell Lung Cancer Panel Chair, Dr. David Ettinger, the Alex Grass Professor of Oncology at The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, who presented an update on the recommendations of the NCCN Guidelines for Non-Small Cell Lung Cancer. Dr. Ettinger's presentation also featured a talk entitled "Small Cell Lung Cancer: Challenges for an Emerging Orphan Disease."

The NCCN Guidelines for Breast and Pancreatic Cancers were presented. Dr. Al Benson, former Chair of the NCCN Board of Directors and Associate Director for Clinical Investigations for Robert H. Lurie Comprehensive Cancer Center of Northwestern University, lectured on the latest updates to the Pancreatic Guideline and

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provided his perspective regarding adjuvant therapy in pancreatic disease.

NCCN Breast Cancer Panel Chair Dr. Robert Carlson provided the NCCN Guidelines for Breast Cancer update and an insightful review of “Triple Negative Breast Cancer Biology, Treatment, and Research.” Dr. Carlson serves as Professor, Division of Medical Oncology at Stanford Comprehensive Cancer Center.

Dr. David Ilson, Attending Physician and Professor at Memorial Sloan-Kettering Cancer Center, updated gastric cancer specialists on the latest NCCN Guidelines for Gastric Cancer and spoke to the role of irinotecan in chemotherapy. The session also featured updates to the NCCN Guidelines for Colon and Rectal Cancers, presented respectively by Dr. Alan Venook, Professor of Clinical Medicine at UCSF Helen Diller Family Comprehensive Cancer Center, and Panel Chair, Dr. Paul Engstrom, Senior Vice President, Extramural Research Programs at Fox Chase Cancer Center.

Updates to the NCCN Guidelines for Ovarian Cancer were discussed by Dr. Robert Morgan, Panel Chair and Staff Physician, Department of Medical Oncology, at City of Hope Comprehensive Cancer Center. Dr. Morgan also presented on the NCCN Guidelines for Cervical Cancer.

The NCCN Guidelines for Kidney Cancer and immunotherapy in kidney cancer were presented by Dr. Kim Margolin, Member, Fred Hutchinson Cancer Research Center, and Physician and Clinical Investigator at Seattle Cancer Care Alliance.

Dr. Scott Howard, Chair of Pediatric Oncology in Developing Countries at St. Jude Children’s Research Hospital/University of Tennessee Cancer Institute, gave a thought-provoking review of Burkitt’s lymphoma and the urgency of diagnosis. The management of cerebral metastases, challenges in ovarian cancer, and HER2 targeted therapy of metastatic breast cancer were presented by Dr. Ettinger, Dr. Morgan, and Dr. Carlson, respectively. Complementary to the NCCN faculty sessions were lectures by prominent Chinese physicians specializing in each of the presented tumor types. The final session, themed “NCCN Frontiers of Oncology,” which included a collection of forward-looking perspectives from most of the NCCN faculty, concluded the Congress Series in Beijing on April 14, 2011.

The NCCN Guidelines are the recognized standard of care in the United States. Expert clinicians across Asia recognize and apply NCCN Guidelines in practice and have collaborated with NCCN on the translation, adaptation, and implementation of national versions of the NCCN Guidelines. NCCN and cancer-care thought leaders in China have had a long-standing collaboration in the development of the NCCN Guidelines, China Editions, the most authoritative reference for oncology practice in China. Indeed, of the 1.3 million unique visitors to the NCCN Web site ([www.NCCN.org](http://www.NCCN.org)) every year, approximately 250,000 are from Asian countries, with 57,000 unique visitors from Japan and 47,000 from China.

NCCN regularly collaborates with international organizations around the world to create and distribute translations of the NCCN Guidelines, which may include modifications representative of metabolic differences in populations, technological considerations, and regulatory status of agents used in cancer management, such as availabilities of drugs, biologics, devices, and procedures.

To learn more about NCCN’s international initiatives, visit [NCCN.org](http://NCCN.org).