## Journal of the National Comprehensive Cancer Network

## NCCN Announces the NCCN Guidelines for Patients

Patients with cancer and their caregivers have a new resource to help them navigate the maze of treatment options that they often confront. At the NCCN Patient Advocacy Summit in Washington, DC, the National Comprehensive Cancer Network (NCCN) launched its new series of NCCN Guidelines for Patients, consumer-friendly translations of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) outlining appropriate cancer treatment.

"The NCCN Clinical Practice Guidelines in Oncology are recognized by clinicians around the world as the standard for oncology care," said William T. McGivney, PhD, Chief Executive Officer, NCCN. "We are acutely aware of how important it is to provide the same timely, high-quality information to patients who need to understand their cancer treatment options and are thrilled to offer this unique and much needed resource."

The first 2 guidelines released cover breast and lung cancers. Susan G. Komen for the Cure has provided the NCCN Foundation \$160,000 in grant support to develop and distribute the NCCN Guidelines for Patients: Breast Cancer.

"Women who are living with breast cancer today not only have to contend with the reality of their diagnosis, but also have to live in an increasingly complex and changing world. We understand now that breast cancer is not a single disease. You have to know the sub-type of the breast cancer, the stage of your disease and be able to evaluate the options available for you as an individual," said Diana Rowden, Survivorship and Outcomes Vice President at Susan G. Komen for the Cure. "While there are a number of good resources available to these women, only the NCCN Guidelines for Patients provide the level of highly-specific, current information that patients want and need. We are very proud to take a leadership role in supporting these guidelines and making them available to breast cancer patients."

The NCCN Guidelines for Patients: Lung Cancer is named in honor and memory of Dana Reeve, the wife of the late actor Christopher Reeve. Dana died of lung cancer in 2006, seven months after her diagnosis. Her sister, Deborah Morosini, MD, a member of the NCCN Foundation Board, has become an active spokesperson for increased awareness of lung cancer.

"When my sister, Dana, was diagnosed with lung cancer, I assumed, as a physician, that we would be able find the information we needed to sort through all the various treatment options," said Deborah Morosini, MD. "It turned out to be much more difficult than I thought. These guidelines will fill a huge gap for patients and the people who are supporting them and will be an incredibly valuable tool in making them more knowledgeable partners in their own treatment. Losing my sister was a devastating experience for our whole family, but it is very meaningful to all of us to have these guidelines named in her honor and memory."

The NCCN Guidelines are developed by multidisciplinary panels of experts from NCCN Member Institutions and feature algorithms or "decision trees" that address every appropriate treatment option from initial work up throughout the course of the disease. The NCCN Guidelines for Patients translate these professional guidelines in a clear, step-by-step manner that patients can utilize as the basis for making decisions and discussing options with their physicians. By the end of 2010 or early 2011, NCCN anticipates releasing additional NCCN Guidelines for Patients for melanoma, non-Hodgkin's lymphomas (NHL), colon and prostate cancers, and ultimately plans on having patient versions for all major adult cancer sites.

The NCCN Guidelines for Patients are available at NCCN.com, which also features enhanced content for patients and caregivers. A link to the NCCN Guidelines for Patients: Breast Cancer will also be available at komen.org. Additionally, NCCN is planning to develop hard copy versions of the NCCN Guidelines for Patients.

Cont. on page xxxviii.

October 2010

The NCCN Guidelines for Patients program is the first major undertaking of the NCCN Foundation, formed in 2010 to support initiatives and research in patient education, survivorship, and quality of life and to assist in developing the next generation of clinical expertise by providing opportunities for young clinicians, investigators, and nurses to participate in NCCN Guidelines Panels. The NCCN Foundation continues to seek philanthropic support for these efforts.

Melanoma survivor, ABC news anchor, and chair of the NCCN Foundation Board of Directors Sam Donaldson emphasized the ease of use of the NCCN Guidelines for Patients stating, "Rather than having to consult numerous sources, patients now have straightforward access to a wealth of information in a convenient, clearly-written format."

In an effort to further communicate with patients, NCCN has launched a Facebook page. This page, the first social media-related NCCN endeavor, will feature patient-relevant articles and news. Visit NCCN on Facebook at NCCN Facebook Page

To access the NCCN Guidelines for Patients free of charge, visit NCCN.com

## Compendia Usage and Off-Label Indications Focus of NCCN Oncology Summit

NCCN announced that key policy organizations and thought leaders will convene to discuss the critically important subject of the use of drugs and biologics for indications that are supported by evidence and compendia, but that are beyond the indications listed in the FDA label. This invitation-only Policy Summit will be held on December 17, 2010 at the National Press Club in Washington DC.

The use of drugs for indications beyond those stipulated in the FDA label has been a physician prerogative that the FDA has approved of for more than 30 years. A high percentage of the use of drugs and biologics in cancer care is off-label. The introduction and utilization of many innovative drugs and biologics in oncology practice, combined with their significant expense, has focused the attention of payors and other involved constituencies on processes and programs that will facilitate the appropriate, effective, and efficient use of such agents. Since the late 1980s, drug compendia have been one mechanism to arbitrate such appropriate use in terms of both payors and providers.

The NCCN Oncology Policy Summit will examine the use of compendia by public and private payors, looking at issues such as categories of evidence, compendia processes, and availability of data, among others. Further, the Summit will explore the existing guidance, and surrounding interpretation, on the legality of dissemination of various clinical and scientific documents that contain off-label uses. Finally, in a roundtable with the four Compendia, the Summit will discuss the future of compendia, their use, and their response to current and future events such as the advent of molecular markers, calls for greater public transparency, availability of compendia information, use and categorization of existing evidence, and use of comparative effectiveness.

"The availability of a broad therapeutic arsenal of innovative drugs and biologics is essential for the treatment of the vast array of diseases that we call cancers. It also is critical that these agents be used appropriately and efficiently," said William T. McGivney, PhD, CEO of NCCN. "NCCN believes that many of the issues surrounding the off-label use of drugs and biologics need to be addressed in a public forum with all involved constituencies present and participating. This will be achieved by the NCCN Oncology Policy Summit."