New, Reliable Source of Free Information for People with Liver, Gallbladder, or Bile Duct Cancer, Offered by NCCN

NCCN has released a brand-new resource to help people with liver, gallbladder, and bile duct cancers better understand the critical decisions they make about their care. This new edition of the NCCN Guidelines for Patients takes the evidence-based, expert consensus treatment recommendations from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines), and creates a patient-friendly version with easy-to-follow wording. Funding was provided by the NCCN Foundation, with sponsorship from the Global Liver Institute, with content endorsed by the Cholangiocarcinoma Foundation.

“An essential element of patient empowerment is accessible, actionable, high-quality information,” said Donna R. Cryer, JD, President & CEO, Global Liver Institute. “The Global Liver Institute is proud to work with NCCN to provide this information to support liver and bile duct patients with cancer and their families in the hope that together we can make the cancer journey easier and more successful.”

More than 50,000 people in the United States are diagnosed every year with a cancer involving the liver, gallbladder, or bile ducts—collectively known as hepatobiliary cancers.¹ Globally, both the number of incidents and the number of deaths from liver cancer are on the rise, despite declining numbers for both in cancer overall.² This correlates with rising rates of hepatitis B and, more frequently, hepatitis C infections, which is often a precursor to liver cancer.³ Metabolic disorders (including obesity, diabetes, and nonalcoholic fatty liver disease) are also associated with increased risk of liver cancer,^{4,5} and there is growing evidence for an association with nonalcoholic steatohepatitis.^{6,7} Additionally, people with liver cancer often also suffer from underlying cirrhosis, which can create limitations for their cancer treatment options. Common treatments include liver transplantation, surgery, radiation, ablation/embolization, or drug therapy.

“When people are diagnosed with liver cancer, patients hope their doctor will be able to present them with a definitive best course of action, but there are often multiple treatments from which to choose. The best choice for any given individual has been to take into account their disease status, symptoms, laboratory results, and, of course, personal preferences,” explained Al B. Benson III, MD, Robert H. Lurie Comprehensive Cancer Center of Northwestern University. Dr. Benson chairs the NCCN Guidelines Panel for Hepatobiliary Cancers. “Patients and caregivers are often taken by surprise with the diagnosis. Those with hepatitis C might not even know that they’d ever been exposed to it. Some go from being completely healthy to suddenly facing this life-changing event. People need a reliable source of information that’s readily available, free-of-charge, to help them weigh the pros and cons, and interpret the complex medical choices in front of them.”

Dr. Benson cautioned against relying on the internet in general for information about cancer treatments, since that information can be highly variable, and at times incorrect. He also stressed the important role for public health efforts in preventing liver cancer. He cited the hepatitis B vaccine as one key cancer prevention tool, as well as more broad-based education around the long-term effects of heavy alcohol consumption.

The content in the NCCN Patient Guidelines is vetted by expert clinicians from the 27 NCCN Member Institutions. The booklets include patient-friendly elements, such as questions to ask the doctor, a glossary of terms, and medical illustrations. They are available free-of-charge at NCCN.org/patients or via an app for smartphones and tablets. Print copies of the NCCN Guidelines for Patients are available on Amazon for a nominal fee. The library currently contains guidelines for >40 different cancer types, including breast, colon, lung, and prostate cancers.

NCCN Guidelines for Patients and NCCN Quick Guide sheets DO NOT replace the expertise and clinical judgment of the clinician.

Cont. on page xxx.

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July 2018

Cont. from page xxvii.

To help support these tools, visit NCCN.org/patients or text “GIVE” to 856-FOR-NCCN (856-367-6226).

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NCCN Convenes Summit on Providing High-Quality Cancer Care in an Evolving Policy and Tech Landscape

NCCN's Oncology Policy Program hosted a summit focused on pragmatic approaches for providing the highest quality cancer care possible in the face of changing laws and technology. The program, “Policy Strategies for the ‘New Normal’ in Healthcare to Ensure Access to High-Quality Cancer Care,” took place at the National Press Club in Washington, DC, and included diverse perspectives from clinicians, lawmakers, patient advocates, and others. FDA Commissioner Scott Gottlieb, MD, provided the opening keynote address. Congressmen Mark DeSaulnier (D-CA) and Ted Poe (R-TX), co-chairs of the Congressional Cancer Survivors Caucus, offered their perspectives as lawmakers.

“Our hope is that everyone comes away from this summit with a fuller understanding of some of the complex issues involved in delivering the best cancer care possible to the largest number of people,” said Robert W. Carlson, MD, Chief Executive Officer, NCCN. “At NCCN, we create opportunities for speakers with varying viewpoints to have a face-to-face conversation about patient access to high-quality cancer care. By including speakers with diverse perspectives, we can explore how policy and practice need to evolve in order to provide everyone with access to safe, effective cancer care.”

One key topic of conversation throughout the summit was the role patients and caregivers have in determining their own most valuable path, and how best to equip them for it.

“Empowered, knowledgeable patients and families are our best defense against shoddy cancer care,” said Joseph Alvarnas, MD, City of Hope Comprehensive Cancer Center. “We have a responsibility to educate patients and families who are in search of high-quality care, as to what constitutes true quality in relation to their cancer journey.”

Survivor, health advocate, and consultant Stefanie Joho agreed. “Physicians and patients need to be partners — effective communication between them is key,” she said. Joho also pointed out that people with cancer aren't the only ones in need of education, particularly when confronted with new treatment methods. “Cutting edge therapies require the constant advancement of continuing education for oncologists.”

Stephanie Farnia, MPH, The American Society for Blood and Marrow Transplantation, offered some of their ‘lessons learned’ on provider perspectives from the launch of CAR T-cell therapy, namely, “The Medicare inpatient reimbursement system, in its current form, is not set up well to deal with these leaps in technology and associated high price points. New treatments that launch without a complete reimbursement and coding plan

Cont. on page xlii.

July 2018

Cont. from page xxx.

will face a lag in uptake by providers. Therefore, companies need to understand—and work to remedy—the financial pressure the high price of innovations can put on providers.”

Speakers and panelists throughout the summit also emphasized the importance of clinical trial participation. “Recent advances in cancer care have been driven by the identification of targetable mutations, harnessing the immune system’s ability to fight cancer, and improved symptom management,” explained Pavan Reddy, MD, Kansas Society of Clinical Oncology, Cancer Center of Kansas. “These advances were fueled by drug development and testing through clinical trials. It is essential to encourage patient participation in these trials in order to deliver high-quality and personalized cancer care while continuing to advance the science.”

Joho agreed, stating “Clinical trials must be destigmatized.”

“Innovations in the oncology space have been accelerating in recent years,” said NCCN’s Director of Policy, Alyssa Schatz, MSW. “It’s exciting, but it also requires constant adaptation.” Schatz explained that the last decade has also seen many changes to healthcare policy and payment models, from the shifting of authority away from the federal government toward individual states, as well as the move from fee-for-service payment models toward value-based models of care.

During the summit, NCCN debuted results from a survey of NCI-Designated Cancer Centers regarding their experience with exchange marketplace coverage plans, conducted from December 2017 through January 2018 by Avalere Health. Of the 29 responding centers across 21 states plus Washington, DC, 25 were only in-network for some, not all, of the ACA exchange plans available in their state. Two more were excluded from all of their state’s exchanges. The percentage of centers that were excluded despite attempting to be in-network increased slightly from 2017 to 2018.

“This tells us that we have to be concerned with consumer education efforts in order to make sure people who purchase plans on an exchange fully understand any limitations when they sign up,” said Schatz. “If people opt for lower premiums, they need to be made aware if that could restrict where they’re eligible to be treated or lead to higher out-of-pocket costs in the future.”

The panel discussions were moderated by Clifford Goodman, PhD, The Lewin Group, and also included input from Joseph Antos, PhD, American Enterprise Institute; Jennifer Carlson, The Ohio State University Wexner Medical Center; John Cox, DO, Parkland Health and Hospital System, UT Southwestern; Elizabeth Franklin, LGSW, ACSW, Cancer Support Community; Anna Griffin, Kite, A Gilead Company; Meghan Gutierrez, Lymphoma Research Foundation; Caron A. Jacobson, MD, Dana Farber Cancer Institute/Brigham and Women’s Hospital; Ron Kline, MD, Center for Medicare and Medicaid Innovation (CMMI); Kavita Patel, MD, Brookings Institute; and Michael Ybarra, MD, PhRMA.

NCCN’s next policy summit, “Policy Challenges and Opportunities to Address Changing Paradigms in Cancer Care Delivery,” will take place on September 13, 2018, at the National Press Club. Then on December 10, 2018, NCCN will host a Patient Advocacy Summit to address “Advocating for Equity in Cancer Care.”

Visit [NCCN.org/policy](https://www.nccn.org/policy) for more information, and join the conversation online with the hashtag #NCCNPolicy.