NCCN Expands Resources for Treating Rare Cancer Types

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NCCN has announced the publication of new NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Ampullary Adenocarcinoma. This evidence- and expert consensus–based resource follows the recent publication of new NCCN Guidelines for Malignant Peritoneal Mesothelioma, bringing the total number of clinical guidelines to 83.

“We know there’s a real need to share evidence-based expert recommendations for some of these rarer tumor types, which oncologists see infrequently and may not have the opportunity to keep as up to date with,” said NCCN Chief Medical Officer Wui-Jin Koh, MD. “NCCN Guidelines were downloaded >13 million times overall in 2021. Guidelines for the most common cancers, including breast, lung, colon, and prostate tend to be referenced the most, but we do hear from clinicians who would like more guidance to help patients with less common cancers achieve the best possible outcomes.”

NCCN Guidelines are the recognized standard for clinical recommendations and policy in cancer management and the most thorough and frequently-updated clinical practice guidelines available in any area of medicine. They are kept up-to-date by >1,700 subject matter experts from across the 31 NCCN Member Institutions, who contributed an estimated 40,000 hours across 60 different interdisciplinary panels over the last year. NCCN Guidelines are available free-of-charge for noncommercial use at NCCN.org or via the Virtual Library of NCCN Guidelines App.

Early detection and prompt treatment can make a big difference in improving outcomes for ampullary tumors, which occur around a small opening at the junction of the duodenum, bile duct, and pancreatic duct. Ampullary adenocarcinoma accounts for <1% of all gastrointestinal malignancies, but tends to have a higher cure rate than other biliary tract and pancreatic cancers that may occur in the same general area.[1–5]

Malignant peritoneal mesothelioma (MPeM) is a rare, aggressive cancer that occurs in the lining of the abdomen (peritoneum) in approximately 600 patients every year in the United States. The new guidelines include an extensive section on the specific pathology tests that can be used to accurately identify MPeM, because it is challenging to diagnose due to its rarity and the fact that symptoms mimic other diseases such as ovarian cancer. There is currently no recognized staging system for MPeM to assist with prognosis and treatment.[6–8]

“It can be hard for people with rare diseases to get the attention they deserve, but at NCCN we are doing all that we can to support people with any type of cancer, along with their loved ones and healthcare providers,” said Dr. Koh. “The NCCN Guidelines currently cover 97% of cancer cases in the United States, and we’ll keep adding more guidelines.”

In addition to the growing library of clinical guidelines, NCCN recently published new and updated rare disease resource to empower patients and caregivers. Newly-posted NCCN Guidelines for Patients: Systemic Mastocytosis (a rare mast cell disorder) and updated NCCN Guidelines for Patients: Small Cell Lung Cancer are available as a free download at NCCN.org/patientguidelines or the NCCN Patient Guides for Cancer App, or printed for a nominal fee via Amazon.com.

Another element in NCCN’s efforts to improve patient care and safety for both rare and common cancers are the NCCN Chemotherapy Order Templates

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(NCCN Templates), which recently surpassed 2,000 regimens. These resources provide user-friendly information on chemotherapy, immunotherapy, supportive care agents, monitoring parameters, and safety instructions, based on recommendations in the NCCN Guidelines. They help reduce medication errors and anticipate and manage potential adverse events, while standardizing patient care. Learn more at NCCN.org/templates.

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Nearly 100 Cancer Organizations Urge Congress to Fund Cancer Moonshot Initiatives

Nearly 100 cancer organizations representing patients, providers, and researchers sent a letter to the president and congressional leadership today in support of funding the Cancer Moonshot initiative. The letter details the urgent need for funding especially in light of delayed screenings, treatments, and research caused by the COVID-19 pandemic. It also makes clear the unique opportunity to accelerate the pace of discovery with additional resources.

"The Moonshot initiative's goals of cutting the cancer death rate in half through prevention, early detection, innovation, and addressing inequities is laudable, timely, and achievable, but only with the allocation of adequate funding to support these initiatives," the letter states.

It notes that >9.5 million people have missed cancer screenings because of the pandemic, including dramatic drops in the number of cervical, colorectal, breast, prostate, and lung cancer screenings and that, "a reignited Cancer Moonshot is timely to encourage and support the significant effort required to address those who have missed these important screenings."

It also highlights the importance of creating the Advanced Research Project Agency for Health (ARPA-H) to accelerate cancer research and innovations in treatment, along with measures to increase HPV vaccination and improve the nation's nutrition and increase physical activity.

"We enthusiastically support this commitment to 'end cancer as we know it' and are prepared to work with bipartisan lawmakers to enact public policies that will achieve this goal," said Robert W. Carlson, MD, Chief Executive Officer, NCCN, one of the organizations coordinating this outreach. "Improving equitable prevention, early detection, and treatment will help us continue to

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"A bold goal requires bold action, and we are eager to help achieve the Cancer Moonshot's full potential," said Lisa Lacasse, president of the American Cancer Society Cancer Action Network. "Cancer affects everyone, but it doesn't affect everyone equally and there is significant progress to be made to ensure everyone has a fair and just opportunity to prevent, detect, treat, and survive cancer. We look forward to working with the administration and Congress to pass proven public health policies that bring us all closer to a healthier future with less death and suffering from this disease."

Read the letter at NCCN.org/moonshot.

NCCN and ACS CAN previously teamed up to share the message that "Cancer Won't Wait and Neither Should You" to encourage recommended cancer screenings that dropped dramatically during the COVID-19 pandemic. President Biden echoed this concern while announcing the reignited Cancer Moonshot initiative, noting that >9.5 million people have missed cancer screenings because of the pandemic and recent studies have found a dramatic decrease in the number of cervical, colorectal, breast, prostate, and lung cancer screenings. Learn more about the urgent need to resume routine cancer screening, and the latest expert guidance on when to do so, at NCCN.org/resume-screening.

Reducing Hereditary Cancer Act Promises to Expand Access to Cancer Screenings and Interventions for High-Risk Medicare Beneficiaries

> "With the ability to identify individuals who carry these mutations, there is an opportunity to prevent or detect cancers earlier, when they are easier and less expensive to treat.

United States Senators Ben Cardin (D-MD) and Lisa Murkowski (R-AK) have introduced the Reducing Hereditary Cancer Act, bipartisan legislation to expand access to medically-appropriate genetic testing to determine an individual's risk of developing hereditary cancer—and access to evidence-based medical care to reduce risk for those who have a predisposing genetic mutation. The Senate bill is identical to HR 4110, introduced in the House in June of 2021.

Medicare currently covers genetic testing only for people who have already been diagnosed with cancer, regardless of a history of cancer or known genetic mutations in their family. It does not cover medically necessary cancer screenings or risk-reducing interventions for individuals who have a genetic mutation increasing their cancer risk.

FORCE: Facing Our Risk of Cancer Empowered and NCCN are proud to advocate for this legislation that would remedy a longstanding Medicare gap, ensuring that beneficiaries at increased risk of cancer have access to standard-of-care genetic counseling, testing, screening, and risk-reducing interventions.

This proposed law will enable coverage of guideline-recommended genetic testing for inherited mutations known to increase cancer risk in two Medicare populations: those with a known hereditary cancer mutation in their family as well as those with a personal or family history that suggests a higher risk for hereditary cancer. For Medicare beneficiaries who have one of these gene mutations, the law will enable coverage of increased cancer screening

(eg, breast MRIs, more frequent colonoscopies) and risk-reducing surgeries (eg, hysterectomy).

"With the ability to identify individuals who carry these mutations (via a simple saliva or blood test), there is an opportunity to prevent or detect cancers earlier, when they are easier and less expensive to treat," explains Lisa Schlager, Vice President of Public Policy for FORCE. "Access to risk-based screening and preventive medicine is critical. We believe this effort aligns with the goals of the Cancer Moonshot and the President's Cancer Panel report on 'Closing the Gaps in Cancer Screening.' This legislation will help minimize barriers to care, ultimately reducing health disparities while saving lives and money."

Inherited genetic mutations (eg, *BRCA*, *ATM*, *CHEK2*, *PALB2*, Lynch syndrome) are associated with an increased risk for a number of malignancies, including breast, colorectal, prostate, pancreatic, ovarian, stomach, and endometrial cancers. Up to 10% of all cancers are due to a cancer-related genetic mutation, although that number is significantly higher for certain cancers like ovarian, in which nearly 25% of cases are due to an inherited mutation. The more prevalent cancer-related genetic mutations are found in approximately 1 in every 300 Americans, with certain populations and ethnicities having higher rates.

"This bipartisan bill will improve early detection of hereditary cancers and allow focused, enhanced preventive strategies to reduce unnecessary pain, suffering, and death," said Robert W. Carlson, MD, Chief Executive Officer of NCCN—a nonprofit alliance of leading cancer centers that publishes free, frequently updated expert-consensus guidelines on genetic/familial risk reduction and other topics. "Medicare beneficiaries deserve access to the same standard of preventive care and early detection as Americans with private insurance. We applaud the sponsors of the 'Reducing Hereditary Cancer Act' for taking action to ensure Medicare recipients have equitable access to healthcare that follows the latest evidence-based guidelines. We are proud to join with FORCE and other leading cancer organizations to advocate for life-saving access to expert-recommended care. Genetic testing for people with familial risk of cancer, followed with appropriate screening and risk-reducing interventions, will save lives and avoid future costly treatments."