

NCCN Patient Advocacy Summit Emphasizes Treating Every Cancer Patient as an Individual

On December 10, 2020, NCCN hosted an annual patient advocacy summit featuring Senator Chris Van Hollen (D-MD) and Congressman Buddy Carter (R-GA), which was streamed online. Every year, the NCCN Policy department invites people from across the oncology ecosystem to share their perspectives on improving the quality and efficiency of cancer care so that patients can live better lives. This year's virtual summit focused on putting the "personal" into "personalized care" while exploring how the needs of people with cancer can vary across the lifespan.

"We work with patient advocacy organizations year-round to ensure our policy team is advocating for policies that address the most pressing issues for people with cancer and their caregivers," said Alyssa Schatz, MSW, Senior Director of Policy and Advocacy for NCCN and a participant in the roundtable discussion titled "Identifying Policy and Practice Solutions for Patients Across the Lifespan." "This summit gives us a chance to learn from one another and speak collectively to our audience of providers, payers, and policymakers. A key takeaway from [the] conversation is the reminder to treat the person—not the demographic—while also recognizing that people in some demographics may face additional obstacles to quality cancer care."

"Cancer survivors are more than their age, gender, or disease," explained keynote speaker Jan S. White, Cancer Survivor and Patient Advocate. "Assumptions around age and gender often figure into care teams' expectations for survivorship, but if you have not asked your patients about their goals for how they want to live following treatment, you are missing an important step. Their answers will surprise you."

The idea of recognizing everyone's unique set of circumstances was echoed by Danielle Pardue, a panelist who spoke on behalf of caregivers: "The best way to support a caregiver is to take the time to understand the individual needs and strengths of each caregiver and patient. No plan of care for any patient can be completely successful without the support of one or more caregivers, especially at home. Providers need to take both the patient's preferences and the caregiver's abilities into account when determining their treatment recommendations."

Pardue also pointed out: "Every problem does not necessarily have a solution; caregivers should be encouraged to share what they need so that solutions can be sought, but shouldn't be discouraged from sharing when solutions are hard to come by. Sharing experiences is in itself a therapeutic experience for overwhelmed caregivers. There is great power and healing in venting because we understand the world through the stories of others."

Speakers also looked at how members of various racial, ethnic, or socio-economic groups can face some common or recurring barriers to care that must be addressed.

"We cannot separate social, racial, and economic inequality from the adult cancer journey," said Darcie Green, Executive Director of Latinas Contra Cancer. "The clients we serve face predictable and preventable systemic barriers to cancer care. Navigating cancer can be challenging enough without also having to worry about how you will feed your family, pay rent, absorb income loss, or overcome the obstacles that exist within the healthcare system. The COVID-19

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Virtual #NCCNPolicy summit from NCCN explores how the needs and wishes of people with cancer can vary from group to group and person to person across all ages.

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Many of the speakers focused particularly on how a person’s age at the time of diagnosis can result in different options or approaches for treatment, for instance older patients, who are more likely to have additional, unrelated health concerns, or may face implicit bias based on their age.

“As we refine our understanding of tumor biology and tailor therapy to the molecular subtype of each tumor, we must remember factors outside of the actual treatment that significantly affect outcomes,” observed Efrat Dotan, MD, Fox Chase Cancer Center, Chair of the NCCN Guidelines Panel for Older Adult Oncology. “Especially when treating older adults with cancer, evaluating all the domains that affect their care—and addressing any deficiencies—will result in truly personalized medicine and improved outcomes.”

“Cancer is a disease of aging, yet older patients have not shared in the benefits of many modern cancer treatments, and remain woefully under represented in clinical trials,” said Hyman Muss, MD, University of North Carolina Lineberger Comprehensive Cancer Center. “It is the obligation of all of us to fix this in order to guarantee that our older cancer patients get the care they need.”

“We know how important it is to make sure clinical trials enroll a broad representation of patients across age, race, and ethnicity,” agreed Maura Dickler, MD, Lilly Oncology. “At Lilly, we are committed to reducing the barriers that limit diversity in clinical trial enrollment, including working to ensure our trial sites are closer to patients, utilizing new forms of telehealth when appropriate, and broadening eligibility criteria so we are not excluding patients who have additional health conditions.”

There are also unique concerns for cancer survivors who were first diagnosed during childhood or adolescence. Panelists discussed the confusion that can arise over what happens once patients complete active treatment. That’s where survivorship care plans and clinical practice guidelines on preventing or managing recurrence and side effects can play an important role.

“Effective transition of care in cancer survivors from oncologists to primary care physicians can make a significant difference in early detection of late effects. You can’t find something that you are not looking for,” said Aarati Didwania, MD, MSCI, Robert H. Lurie Comprehensive Cancer Center of Northwestern University.

Speakers at the summit also touched on current events impacting cancer care including the upcoming Supreme Court ruling on the Affordable Care Act and the long- and short-term impact of the COVID-19 pandemic on cancer care. The virtual discussions were moderated by Clifford Goodman, PhD, The Lewin Group, and also included Phylcia L. Woods, JD, MSW, from the Cancer Support Community.

Representatives from the Cancer Hope Network, Patient Empowerment Network, and Fight Colorectal Cancer presented information about age-specific resources intended to increase access to recommended screening, improve health literacy, and provide peer-to-peer counseling services. Dottie Shead, MS, from NCCN’s patient information department discussed existing NCCN Guidelines for Patients across cancer types and supportive care topics, including symptom management and age-related care for adolescents and young adults. Shead also previewed the soon-to-

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publish patient and caregiver guidelines focused specifically on survivorship, including guidance on posttreatment wellness recommendations, and monitoring and treating the late and long-term effects that can arise from cancer care.

Visit [NCCN.org/patients](https://www.nccn.org/patients) to learn more about free resources from NCCN. Visit [NCCN.org/policy](https://www.nccn.org/policy) for more on the ongoing work from the NCCN Policy and Advocacy Department and save-the-date for future summits and events. Join the conversation online using the hashtag #NCCNPolicy.

NCCN Announces Research Projects Exploring Axitinib in Various Cancers, in Collaboration with Pfizer

NCCN Oncology Research Program (ORP) announced 4 projects selected to receive funding for clinical evaluation of axitinib. Axitinib, a small molecule indazole derivative, is an oral multi-targeted tyrosine kinase inhibitor of vascular endothelial growth factor (VEGF) receptors 1, 2, and 3. NCCN issued the initial Request for Proposals and convened a Scientific Review Committee from across NCCN Member Institutions to select projects. The studies will receive funding and oversight from Pfizer.

The following projects were selected:

- Phase II Study of Axitinib + Ipilimumab in Advanced Melanoma
 - *Zeynep Eroglu, MD, Moffitt Cancer Center*
- Single-arm Phase II Study of Axitinib, Avelumab, and Bavituximab in Advanced HCC
 - *David Hsieh, MD, UT Southwestern Simmons Comprehensive Cancer Center*
- Phase II Study of Axitinib + PD-1 Blockade in Mucosal Melanoma with Adaptive Phase I Escalation in Select Progressors
 - *Alexander Shoushtari, MD, Memorial Sloan Kettering Cancer Center*
- Phase I-II Study of Hepatic Chemoembolization With Irinotecan-Loaded Drug-Eluting Microspheres (DEBIRI) Plus Axitinib and Hydrochloroquine for Liver-Dominant Metastatic Adenocarcinoma Of The Colon And Rectum
 - *Michael Soulen, MD, Abramson Cancer Center at the University of Pennsylvania*

“We’re particularly interested in learning more about the efficacy of axitinib in combination with various other anti-cancer agents, that may exploit its specific pharmacokinetics,” said Wui-Jin Koh, MD, Chief Medical Officer, NCCN. “These innovative studies will add to our knowledge base for treating challenging cancer presentations, as part of our ongoing exploration into how to improve patient outcomes. All of the selected researchers should be commended for their meritorious proposals.”

The projects are set to begin by August 2021.

The NCCN ORP fosters innovation and knowledge discovery that improves the lives of people with cancer and supports preclinical, translational, clinical research and quality improvement projects in oncology at NCCN Member Institutions. In an effort to improve collaboration in cancer research, the NCCN ORP also maintains a shared resources website and an informed consent database. For more information, visit [NCCN.org/orp](https://www.nccn.org/orp).

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NCCN ORP announces selected studies on adding an oral VEGF inhibitor to treatment for melanoma, colorectal cancer, and hepatocellular carcinoma.

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New NCCN Guidelines for Patients: Survivorship series provides expert advice to help cancer survivors sustain better health while monitoring for any long-term side effects or recurrences.

New Resource for Survivors From NCCN Helps Guide Life After Cancer Diagnosis and Treatment

NCCN announced the publication of new, free informational resources on health and wellness for cancer survivors. These 2 new NCCN Guidelines for Patients are focused on healthy living and managing late and long-term side effects, and include appropriate ongoing screening for recurrence. The books are available for free to view and print at [NCCN.org/patients](https://www.nccn.org/patients) or via the NCCN Patient Guides for Cancer App, thanks to funding via the NCCN Foundation and sponsorship by Good Days. The books *Survivorship Care for Healthy Living* and *Survivorship Care for Cancer-Related Late and Long-Term Effects* provide jargon-free roadmaps for what comes next after initial cancer diagnosis and therapy.

“Getting a cancer diagnosis is scary. Surviving cancer can be even more scary,” said Ethan Zohn, 2x Cancer Survivor and Stem Cell Transplant Recipient, Winner of SURVIVOR Africa & Social Entrepreneur (@EthanZohn on Twitter and Instagram). “There are loads of uncertainty and invisible scars that need healing. That’s why I work tremendously hard to maintain my mental, physical and spiritual health in survivorship. Surrounding myself with family and friends, exercising, and getting out in nature has helped create balance in my life.”

“Just because initial therapy is over, doesn’t mean that it’s done,” explained Crystal Denlinger, MD, Fox Chase Cancer Center, Chair of the NCCN Guidelines Panel for Survivorship. “Treatment may end, but fatigue, neuropathy, and other effects can linger. For some, cancer survivorship means long-term management as they continue to live with and through disease. These guidelines are applicable for survivors who are disease free as well as those living with cancer. They are far reaching across all cancer types, genders, and ages.”

“These guidelines include information on healthy living after a health crisis; which are good recommendations even for people who’ve never been diagnosed with cancer,” added Tara Sanft, MD, Yale Cancer Center/Smilow Cancer Hospital, Vice Chair of the NCCN Guidelines Panel for Survivorship. “We want everyone to make a realistic plan to start moving more. It sounds simple, but we have really good data that exercise can reduce recurrence, even in people who didn’t exercise before diagnosis. It’s never too late.”

The guidelines pay heightened attention to mitigating risks of cardiovascular disease. There is also information for primary care providers to appropriately advise survivors, in collaboration with oncologists, to help them stay up-to-date on evolving screening recommendations.

Drs. Denlinger and Sanft stress that good survivorship care doesn’t have to wait until remission; in fact, they advocate taking care of the whole person beginning at diagnosis. They point out that preventive strategies include vaccination and appropriate screening as well as health behaviors.

“We know people do better overall when they’re healthier,” said Dr. Sanft. “We can improve longevity by addressing all of the factors that lead to poorer health and taking steps now to reduce long-term effects from treatment.”

This position is echoed in the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Survivorship, the trusted evidence- and expert-consensus based clinical practice guidelines that serve as the blueprint for these new patient guides. NCCN recognizes that the population of cancer survivors is growing rapidly, due to both an increase in diagnoses, and improving care methods that keep more people alive for longer. This is resulting in a greater

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need for research into long-term effects from traditional and emerging therapies, with the latter including immune checkpoint inhibitors and CAR T-cell therapy (side effects from both immunotherapy types are covered in recently published NCCN Guidelines for Patients).

There are now more than 50 different books for patients and caregivers from NCCN covering every major type of cancer, along with topics like managing cancer-related distress, nausea and vomiting, and special considerations for adolescents and young adults across all cancer types. Printed versions are available for a nominal fee at Amazon.com in addition to the free digital versions at [NCCN.org/patients](https://www.nccn.org/patients).

NCCN also just released new books for patients and caregivers on bone cancer and primary central nervous system (CNS) lymphoma. The NCCN Guidelines for Patients: Bone Cancer focuses on tumors that start in the bone or cartilage. The book includes treatment recommendations for chondrosarcoma, chordoma, Ewing sarcoma, giant cell tumor of the bone, and osteosarcoma. The NCCN Guidelines for Patients: Primary CNS Lymphoma offers expert diagnosis and treatment information for this uncommon and aggressive form of non-Hodgkin lymphoma that can start in the brain, spinal cord, eyes, or surrounding tissue.

Learn more and help support these and other resources for people with cancer and their caregivers at [NCCN.org/patients](https://www.nccn.org/patients).