Advocates Reveal Cancer Survivorship Challenges and Resources During NCCN's Patient Advocacy Summit

NCCN convened a Patient Advocacy Summit in Washington, DC, on December 1, 2017, to examine the most pressing issues facing cancer survivors and their caretakers and to discuss available resources. Survivors and patient advocates were joined by employers, clinicians, policymakers, and pharmaceutical and biotech industry representatives in front of an audience of more than 150 people.

“Living through and beyond a cancer diagnosis can have a profound effect on people’s physical, psychological, social, economic, and spiritual well-being,” said Robert Carlson, MD, Chief Executive Officer, NCCN, who provided opening and closing remarks. “Providing the best care for these individuals — especially those diagnosed at a very young age — extends well beyond the initial phase of treatment. The good news is that patients are living longer after diagnosis; that means we need to make sure we’re prepared for any long-term concerns.”

The first panel focused specifically on the patient perspective, and was comprised of the following speakers: Kendall Bergman, MA, LiveSTRONG; Yelak Biru, cancer survivor; George Dahlman, JD, Children’s Cause for Cancer Advocacy; Andi Dwyer, BS, Fight Colorectal Cancer; and Linda House, RN, BSN, MSM, Cancer Support Community.

Before delving into issues like survivorship care plans, palliative care, pain management, chronic side effects, and financial toxicity, the panelists discussed the very concept of “survivorship.”

“The word ‘survivor’ may imply that treatment has concluded, but for many cancers, survivors actually need ongoing treatment for the rest of their lives,” explained Mr. Biru, who was diagnosed with multiple myeloma 22 years ago. “Some people find the word too passive. They may, understandably, prefer to call themselves warriors.”

The second panel included the following representatives from various facets of healthcare: Ken Braun, Employers Health Coalition; Crystal Denlinger, MD, Fox Chase Cancer Center; Dorothy Phillips, Florida Society of Clinical Oncology; Julia Rowland, PhD, National Cancer Institute: Office of Cancer Survivorship; Chris Lieu, MD, University of Colorado Cancer Center; and Richard Woodman, MD, Novartis.

The second panel discussed novel survivorship outcomes, and the desire for treatments that leave “minimal residual disease” and lead to “treatment-free remission.”

“From the industry’s perspective, we’re trying to be forward-thinking about long-term care management and maintaining remission,” said Dr. Woodman. “Many cancers become chronic diseases and require multiple lines of therapy. Novel survivorship is about treatment-free intervals and reducing the need for ongoing medication.”

“It’s also very important to determine who handles the ongoing coordination of care for survivors,” according to Dr. Denlinger. “Preventive health and cancer surveillance needs change over time. Care management generally shifts from oncologists to primary care physicians, but it needs to be done in an integrated way, so survivors have all of their healthcare needs addressed.”

The topic of disparities was another key issue for the panel, specifically regarding the different needs of urban and rural populations and people across socioeconomic statuses. When it comes to racial minorities, panelists were concerned about gaps in data, and agreed that more outreach and study is needed for underserved communities. The panelists also discussed the impact of aging baby boomers and the growing survivorship population. Both panels were moderated by Clifford Goodman, PhD, The Lewin Group.

There were additional presentations from the following speakers throughout the event: Katie Brown, OPN-CG, LUNGEvity Foundation; Sarah Cassidy, Cancer Hope Network; Janine Guglielmino, MA, Living Beyond Breast Cancer; Joan McClure, MS, NCCN; Dan Miller, JD, Live by Living; and Megan Murphy, National Ovarian Cancer Coalition.

The survivors and advocacy group representatives offered insights from their own experiences, and provided updates on resources for people with cancer.

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NCCN will host 3 policy summits in Washington, DC, in 2018, as well as an emerging issues roundtable on value-based healthcare models during the 23rd NCCN Annual Conference in March. For more information, visit nccn.org/policy.

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Advancing Cancer Care Around the World

Over the last 3 months, NCCN's Chief Executive Officer, Dr. Robert Carlson, has set foot in 4 different continents and both coasts of North America. His travels are part of increasing efforts to acknowledge the important role the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) play across the planet, with nearly half of the >1 million registered users hailing from outside the United States. More than that, NCCN is always striving to improve resources. Dr. Carlson believes the best way to make the NCCN Guidelines more useful is to literally meet people where they live and work, and learn first-hand about the specific circumstances of their region, from drug regulations to social considerations.

In November, Dr. Carlson participated in the presentation of the NCCN Harmonized Guidelines for Sub-Saharan Africa at a standing room-only session during the African Organisation for Research & Training in Cancer (AORTIC) meeting in Kigali, Rwanda. The conference opened with remarks from Jeannette Kagame, the First Lady of Rwanda.

Hundreds of medical professionals from across Africa and elsewhere converged to learn about this new resource, based on the NCCN Guidelines, and co-created with the African Cancer Coalition (ACC). Local experts took clear ownership of the materials, which present an array of options for cancer care targeted for various resource levels. The enthusiastic crowd members had a key question after the presentations: how can I get involved?

Creating the NCCN Harmonized Guidelines was truly a team effort, which also included collaboration with the American Cancer Society, the Clinton Health Access Initiative, a technology company, and several drug manufacturers. The ACC represents >40 oncologists and health ministers from 12 different countries. Additional NCCN Harmonized Guidelines will be released in 2018, including colon/rectal; esophageal/gastric; head/neck: lip, oral, and oropharynx cancers; antiemesis; and survivorship/wellness.

In addition to traveling to Africa, Dr. Carlson was in Madrid, Spain, in early September for the ESMO conference. One week later, he was in Beijing, China, for the International Forum for Quality Cancer Care, hosted by Oxford University. Moreover, in mid-November, he took part in the India Cancer Congress in Bengaluru, where he met with Dr. GK Rath, head of India's National Cancer Institute.

Dr. Carlson's favorite part from all his travels is getting to meet and interact with so many brilliant, passionate professionals. Each conference provided the opportunity to forge new connections and reinforce partnerships with familiar faces. A common message emerged in each destination: NCCN Guidelines and their derivatives are providing an important bedrock to improve quality and efficiency for cancer-fighting organizations worldwide. The more globally NCCN Guidelines are recognized and utilized, the greater the responsibility to make sure they are helpful, accurate, and accessible to all. It is all part of NCCN's mission to help patients live better lives, wherever they may live.

NCCN Introduces New Guidelines for Patients With a Form of Cancer Associated with HIV and AIDS

NCCN has created a new resource for patients living with HIV who develop AIDS-related Kaposi sarcoma. This newly-released NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) brings the library to 68 NCCN Guidelines. Additional NCCN Guidelines, devoted to overall cancer care for people living with HIV, will be released in early 2018.

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“These new NCCN Guidelines for AIDS-Related Kaposi Sarcoma are a first step to ensuring that people living with HIV receive appropriate and equitable cancer treatment,” said Gita Suneja, MD, Duke Cancer Institute, Co-Chair of the NCCN Guidelines Panel. “NCCN recognizes the urgent need for cancer management guidelines in this special population of patients. The guidelines panel is comprised of experts from NCCN Member Institutions across the United States, including oncologists, HIV specialists, pharmacists, and patient advocates. In compiling these guidelines, we learned a tremendous amount from each other and hope this will benefit clinicians and, most importantly, patients living with HIV.”

The incidence of AIDS-related Kaposi sarcoma in people living with HIV has fallen dramatically in the United States in recent years thanks to advancements in HIV treatments.¹ It is considered an AIDS-defining illness and was famously featured in the movie *Philadelphia*. The disease can be limited to skin lesions, which tend to respond well to treatment, but when they become more advanced, it can be difficult to treat. There are also other types of Kaposi sarcoma that affect HIV-negative individuals; treatment recommendations for those cancers will be included in future updates of the guidelines.

NCCN Guidelines Panel Co-Chair Erin Reid, MD, of UC San Diego Moores Cancer Center, further explained: “The NCCN Guidelines for AIDS-Related Kaposi Sarcoma fill an important gap in guidance for care of this rare but important malignancy. Although incidences have decreased, the disease remains one of the most common cancers occurring in persons living with HIV—not only in patients with newly diagnosed HIV infection or inadequate suppression of HIV, but also in people who otherwise appear to have maximum viral suppression and ‘normal’ CD4+ T-cell counts.”

NCCN made the decision to create a panel devoted to AIDS-related Kaposi sarcoma while working with the African Cancer Coalition (ACC), American Cancer Society, and Clinton Health Access Initiative to create the NCCN Harmonized Guidelines for Sub-Saharan Africa.

“While the medical community has made monumental strides toward reducing the impact of HIV and AIDS, there are still more than a million people living with HIV in the United States today,”² explained Robert W. Carlson, MD, Chief Executive Officer, NCCN. “That patient population is then diagnosed with cancer at a 50% higher rate than people in the general population.³ Our work with the ACC began as a way to help them with some of the particular health issues in their home countries. In the end, it also resulted in us finding new ways to expand our library of guidelines for patients here at home.”

As with all NCCN Guidelines, the NCCN Guidelines for AIDS-Related Kaposi Sarcoma are available free-of-charge for noncommercial use at NCCN.org.

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