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NCCN Patient Advocacy Summit Examines Disparities in Cancer Care and Explores Solutions

NCCN hosted a Patient Advocacy Summit in Washington, DC, on December 10, 2018, focused on advocating for equity in cancer care. The summit included case studies, presentations, and panel discussions, all highlighting the barriers that prevent various populations from achieving better outcomes in cancer care. The speakers also discussed some of the work currently underway to help mitigate those issues.

“Cancer care practices are improving every day, but we have to work together to make sure those advancements are accessible to everyone,” said Robert W. Carlson, MD, Chief Executive Officer, NCCN. “People with cancer can be excluded from optimal care for many reasons, including geographic location, socioeconomic class, sexual orientation and identity, insurance status, unconscious bias, and other aspects beyond their control. That’s why NCCN provides opportunities to learn about the causes of these disparities and to share best practices for addressing them.”

The summit included a keynote address from Lynette Bonar, RN, MBA, BSN, FACHE, CEO of the Tuba City Regional Health Care Corporation—the only hospital on Navajo land—along with Brandon Canyon, who was his mother’s primary caregiver before she passed away due to complications associated with her cancer treatment. They talked about the significant cancer burden facing the Navajo Nation, where 85% of homes are contaminated by uranium from abandoned mines. Navajos living near those mines have higher levels of uranium in their bones than 95% of the American population. Those who develop cancer then need to travel more than 100 miles in order to receive treatment.

The burden of traveling for care was a repeated theme throughout the day. For many rural residents, having to travel 50 miles or more for care can be prohibitive. Potential solutions, including treatment online or by phone, often mean relying on infrastructure and technology that may not exist in their area.

“Community oncology practices, already serving the majority of cancer patients in the United States, are developing various processes to further extend access to all populations,” said Natalie Dickson, MD, FACP, Chief Medical Officer, Tennessee Oncology. “We see the path to success. It will require proper funding and leveraging technology for enhanced interdisciplinary teams, policies supporting health and wellness, and solutions to the high cost of drugs.”

“Equity requires a reduction in the variability of care regardless of where the cancer is treated,” said Christine Weldon, MBA, Director, Center for Business Models in Healthcare; Adjunct Instructor, Northwestern University Feinberg School of Medicine. “It’s imperative to follow evidence-based guidelines for treating the patient’s entire set of needs. At the same time, care must be personalized to the patient’s cancer profile, co-morbidities, practical, supportive, emotional and physical needs.”

Some of those needs could include practicalities like childcare, out-of-pocket expenses, missed paychecks, plus the financial toxicity concerns from the treatment itself, according to the panelists.

“Socioeconomic factors play a major role in a patient’s ability to access quality cancer care for pancreatic cancer, including access to resources, clinical trials, and molecular profiling,” explained Cassadie Moravek, Associate Director of Clinical Initiatives, Pancreatic Cancer Action Network (PanCAN). “PanCAN strives to overcome these barriers and support pancreatic cancer patients through our Patient Central call center, where our Patient Central Associates provide personalized information tailored to each patient’s needs and concerns. That includes access to

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our Know Your Tumor precision medicine service, which is available to all patients regardless of the medical institution where they receive treatment.”

“The Leukemia & Lymphoma Society (LLS) is the leading source of free blood cancer information, education, and support for patients, survivors, caregivers, and healthcare professionals,” said Laura Ortiz-Ravick, Sr. Program Manager, Outreach and Health Promotion, LLS. “LLS is at the forefront of patient and community-focused initiatives that address barriers to care—including health disparities—and ensure access to cutting-edge, affordable, and coordinated treatment for all blood cancer patients. For example, LLS’s Myeloma Link program works to address the significant health disparities that exist among African Americans with multiple myeloma, a blood cancer for which African Americans are twice as likely to be diagnosed as white Americans.”

The speakers also pointed out that the barriers to equitable care aren’t always economic. Historic events like the Tuskegee syphilis experiment have resulted in some cultural mistrust of medical interventions. Patients with language barriers often face added difficulties when participating in shared decision-making. Some patients face conscious or unconscious biases that can have a big impact on their treatment options.

“People always say that ‘cancer doesn’t discriminate,’ but the healthcare system often does,” said Liz Margolies, LCSW, Executive Director, National LGBT Cancer Network. “For instance, the stress and stigma of living as sexual and gender minorities in this culture contributes to increased cancer risks in lesbian, gay, bisexual and transgender (LGBT) people. Once diagnosed, LGBT people consistently show worse outcomes after treatment, resulting from provider and systemic bias, and lack of training in LGBT culture and health.”

The panelists also highlighted how clinical trials are a particular area of need for increasing access to underserved populations.

“As a patient advocacy organization that strives to create equitable access to clinical trials for all patients, we appreciate the opportunity to bring attention to this very important matter,” said Dana Dornsife, Chairman and Founder, Lazarex Cancer Foundation. “At Lazarex, we believe that everyone should have the opportunity to take advantage of the medical breakthroughs in technology that clinical trial participation can provide.”

Despite the many difficulties that exist in the delivery of equitable cancer care, the advocates remained optimistic about the future.

“I’m proud to participate in this event and join this important conversation about health equity,” said Michael Sapienza, Chief Executive Officer, Colorectal Cancer Alliance. “The Colorectal Cancer Alliance continues our commitment to breaking down barriers, empowering all people living with cancer, and ultimately ending cancer as we know it.”

Billy Foster of the Kidney Cancer Association (KCA), who has been living with metastatic kidney cancer for more than twenty years, summed up the summit:

“Everyone deserves equal access to good healthcare. I’m here to bring some understanding to why this isn’t currently the case, and to help find solutions to these inequities. I believe that with the efforts of us all, we can provide the underserved with accessible, quality healthcare.”

The panel discussions were moderated by Clifford Goodman, PhD, of The Lewin Group. Additional speakers included:

- Justine Almada, The HPV and Anal Cancer Foundation
- LeeAnn Bailey, MBBS, PhD, National Cancer Institute- Center to Reduce Cancer Health Disparities
- Shonta Chambers, MSW, Patient Advocate Foundation
- Lauren Corduck, MNO, Oneinfifty

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- Donna Cryer, JD, Global Liver Institute
- Elizabeth Franklin, LGSW, ACSW, Cancer Support Community
- Marc Futterweit, JD, Male Breast Cancer Coalition
- Marcie Reeder, MPH, NCCN Foundation
- Julia Trosman, PhD, MBA, Center for Business Models in Healthcare, University of California, San Francisco
- Gloria Zhang, New Tang Dynasty Television

For more information and a look at upcoming NCCN Policy Summits, visit NCCN.org/policy.

NCCN Oncology Research Program Awarded \$2 Million From Lilly to Study Mechanisms of Resistance to CDK4 & 6 Inhibitors in Breast Cancer Treatment

The NCCN Oncology Research Program (ORP) announces plans to solicit and oversee research projects that evaluate cyclin dependent kinase (CDK)4 & 6 inhibitors in the treatment of hormone receptor-positive (HR+), HER2-negative (HER2-) breast cancer and underlying mechanisms of resistance. Research funding will be provided by a \$2 million grant from Eli Lilly and Company (NYSE: LLY).

“This program is part of our ongoing efforts to improve the lives of people with cancer,” said Wui-Jin Koh, MD, Chief Medical Officer, NCCN. “The NCCN ORP facilitates clinical investigation into important questions. In this instance, we’re managing research to understand mechanisms of resistance to CDK4 & 6 inhibitor treatment in metastatic breast cancer.”

“We are excited to support NCCN to further understand the mechanisms of resistance to CDK4 & 6 inhibitors in advanced breast cancer, which is a central and critically important issue in this treatment landscape,” said Maura Dickler, MD, Vice President of Late Phase Development, Lilly Oncology. “This work with NCCN is an example of our ongoing commitment to optimize treatment for people living with metastatic breast cancer.”

CDK4 & 6 inhibitors have emerged as a key treatment in many patients with HR+ and HER2- metastatic breast cancer. However, resistance to CDK4 & 6 inhibitors, either intrinsic or acquired, can limit their effectiveness. This project seeks to support preclinical and clinical studies that elucidate mechanisms of resistance to CDK4 & 6 inhibitors and provide insights into how this resistance can be overcome or mitigated, resulting in potentially greater efficacy. Lilly will provide abemaciclib, a CDK4 & 6 inhibitor, for studies when needed. This endeavor by the NCCN ORP will utilize the scientific expertise from investigators across the 29 NCCN Member Institutions, and proposals will be reviewed and awarded by a scientific steering committee made up of experts from these NCCN institutions.

Earlier this year, the NCCN ORP was engaged by Lilly for a separate project, seeking scalable, reproducible interventions to address gaps in clinical care for treating gastric cancer. To learn more about the NCCN ORP, including ongoing clinical trials, recent publications, and shared resources, visit NCCN.org/ORP.