action

ACCC Welcomes its Newest Members

Commonwealth Oncology Center
Commonwealth of the
Northern Mariana Islands
Delegate Rep: Tiffany Crisostomo
Website: chcc.health

Lankenau Medical Center
Wynnewood, Pennsylvania
Delegate Rep: Michael Koroscik
Website: mainlinehealth.org/locations/lankenau-medical-center

Main Line Health Cancer Care
Pennsylvania
Delegate Rep: Michael Koroscik
Website: mainlinehealth.org/specialties/cancer-care

PanOncology Community Cancer Centers
Puerto Rico
Delegate Rep: Gabriela Herrans
Website: panoncologytrials.com

Paoli Hospital
Paoli, Pennsylvania
Delegate Rep: Michael Koroscik
Website: mainlinehealth.org/locations/paoli-hospital

Riddle Hospital
Media, Pennsylvania
Delegate Rep: Michael Koroscik
Website: mainlinehealth.org/locations/riddle-hospital

★2024-25★ PRESIDENT'S THEME ★★★

ACCC Board Member Participates in Oncology Center of Excellence Community Forum

Building up to National Black Family Cancer Awareness Week (June 13-19), the US Food and Drug Administration (FDA) Oncology Center of Excellence (OCE) hosted a community forum on May 21. Lailea Noel, PhD, MSW, who sits on the Association of Cancer Care Centers (ACCC) Board of Trustees, and is assistant professor, Meadows Foundation Fellow in Quality of Life in the Rural Environment; director, Institute for Collaborative Health Research and Practice, Steve Hicks School of Social Work; and affiliate assistant professor of Oncology and Health Social Work, Dell Medical School, The University of Texas at Austin, joined oncology thought leaders for a discussion about engaging multiple generations in cancer discourse. Through its diversity initiatives, science and technology, community engagement, and social media campaign—complete with the hashtag #BlackFamCan—the FDA hopes to improve health equity for patients with cancer and their families.

Rea Blakey, associate director, External Outreach and Engagement, OCE, FDA, provided opening remarks before introducing the first speaker of the day: Melissa A. Edwards, PhD, deputy executive director, President's Council of Advisors on Science and Technology, Executive Office of the President, the White House.

For Dr. Edwards, the devastating effects cancer can have on a patient were clear to her early in life following her aunt's diagnosis with the disease. "I did my best to help my aunt navigate her diagnosis as she was exposed to treatments and chemotherapy for the first time," Dr. Edwards said. "[But] I felt helpless in this new, confusing environment because I didn't have a good sense of the resources available to my family." According to Dr. Edwards, when her aunt died, it left a painful, lasting impact, along with a fear of talking about cancer at all.


Dr. Lailea Noel

While attending medical school years later, Dr. Edwards began studying cancer immunology. "That allowed me to combat fear with knowledge," she said. Dr. Edwards acknowledged that for children and young adults, it is easy to shrink back and feel intimidated by a cancer diagnosis. However, she emphasized the importance of the friends and family members of a recently diagnosed patient with cancer, to ask questions, be curious, engage in research, and explore every resource available to them.

Diversity in Clinical Research

Following Dr. Edwards's address, Asma Dilawari, MD, medical oncologist, Division of Oncology 1, Office of Oncologic Diseases, FDA, discussed the issues the FDA hopes to solve with its diversity initiatives. "One of the most rewarding parts since joining the FDA is [developing] all these initiatives that address the problems in private practice," she said. "When you see a problem that has come up for many years, you want to start the change."

According to Dr. Dilawari, one of these issues has been a lack of diversity in the clinical trial pool. "We study drugs and products often on a homogenous population and everyone has access to data, but we don't have enough data," she explained. "A lot of diversity plans have touted working with patients, advocates, and community organizations...to start a conversation from all angles on working together to tackle this problem of underrepresentation in clinical trial research."

According to Dr. Dilawari, the FDA developed diversity plans and guidelines to provide specific measures to companies—that are developing and marketing drugs in the United States—focused on ensuring diverse representation in their clinical trial testing population. The initiatives are designed to spark important conversations among drug developers, patient navigators, and others about diversifying cancer drug research and clinical trials.

Blakey echoed Dr. Dilawari's sentiments about the benefits of the FDA's guidelines while highlighting the need for a collaborative approach to improving clinical trial diversity. "There are limitations on what we, the FDA, can do. So, we need all of you," Blakey said.

A Personal Story

The forum shifted toward the patient experience once more with Bryon Daily, national senior manager of Community Outreach-Myeloma Link, the Leukemia and Lymphoma Society, who discussed the value of patient advocacy. A survivor of cancer, Daily shared his experience as a patient navigating the cancer care continuum.

"My story began in 2018 when I was diagnosed with multiple myeloma. We did not have a history of cancer in my family, so it came as a surprise," he said. "I kept myself in good shape, and I thought I was eating the right things, so I was surprised." Daily believes he was lucky to have a good primary care physician before and following his diagnosis and praised the impact his provider had on his journey.

"My doctor noticed small red flags, and that ultimately led to my diagnosis," he said. "I was also fortunate to have access to a number of life-saving resources, including good health insurance." While Daily had the good fortune of being surrounded by people and systems that guided him through successful treatment, many Black patients with cancer and their families do not.

Approximately 8 months following his diagnosis, Daily had a bone marrow transplant and spent the next 90 days in recovery. According to Daily, those days were filled with thoughts on ways to give back to his community and to advocate for financial literacy among Black families. Now, at the Leukemia and Lymphoma Society, Daily partners with community fixtures like churches and food banks to spread the word about free resources that are available to patients with cancer and their families.

"I appreciate you telling your personal story, because a lot of people don't realize that because they feel good doesn't mean there isn't a need for them to see a health care provider," Blakey said to Daily following his remarks. Then she introduced Dr. Noel to discuss her work, and ACCC's commitment to reimagining community engagement.

The Role of ACCC

"Thank you for the opportunity to be a part of this event," Dr. Noel said. "ACCC's work focuses on those cancer care programs and practices that reach out to different communities across the country, so I think we can be a valuable partner to the FDA." Dr. Noel discussed ACCC's mission to bring together cancer programs and practices nationwide to advance health equity for patients with cancer, with a focus on reaching out to smaller rural communities with minimal access to resources.

Dr. Noel went on to discuss how and why ACCC president Nadine J. Barrett, PhD, MA, MS, senior associate dean for Community Engagement and Equity in Research at the Wake Forest University School of Medicine and Atrium Health, centered her President's Theme on reimagining community engagement and equity in cancer. "In conjunction with this theme—and Juneteenth—ACCC will host a webinar on Tuesday, June 18, during #BlackFamCan week," Dr. Noel said. "Dr. Barrett will join AACI's [Association of American Cancer Institutes] president, Dr. Robert Winn [director, and Lipman chair in Oncology, VCU Massey Comprehensive Cancer Center], to discuss their shared organizational goal of advancing equitable cancer care."

Dr. Noel concluded by sharing her own powerful experience with community work in rural patient populations. Troubled by learning that Black women dying of breast cancer before the age of 40 is a common occurrence, Dr. Noel was moved to bring educational resources and treatment options to patients who are unable to travel to major cities to receive treatment, and expressed how vital the work done in these communities is.

Building Bridges

"As I am sitting here, I am almost in tears. Dr. Noel, Dr. Barrett is my hero. It is scary; it is hard. For most of my community, the closest thing we see to a primary care physician is the emergency room," said B. Angeloe Burch Sr, PhD, executive director, African American Dance Ensemble; CEO, African American Community Collaborative, Inc; president, Durham, NC Branch NAACP; parliamentarian, State NAACP; chair, Families and Communities Rising, Inc. "They don't have someone they can talk to; they don't know these people and these people don't know them. And when cancer comes, it comes hard, so they have to decide if they want treatment or if they want to die."

As the day's final speaker, Dr. Burch discussed how culture and the arts—specifically African American dance—can be a powerful unifier in Black communities and offset the hesitation of having conversations about health care, diagnosis, and treatment.

A cancer survivor himself, Dr. Burch understands firsthand the terrible reality many Black patients with cancer face when given a diagnosis: Do I want to put my family through the stress and trauma of getting expensive treatment, or should I just succumb to the cancer and use that money to care for my children while I still can? "Many patients from my community don't have high-paying jobs or decent insurance," he said. With no way to realistically pay for treatment, many make the difficult decision to forgo it altogether so they can afford to take care of their family.

One method that Dr. Burch has found useful has been appealing to the cultural aspects of community by using African American dance to bring people together. He believes that a community environment like that builds trust instead of fear, the latter often being associated with the health care system. Furthermore, Dr. Burch expressed how important it is to bring in health care providers who care about the members of the community to broach the topic of clinical trials and resources for patients.

As the forum concluded, Luckson Mathieu, MD, provided closing remarks about the role of the Oncologic Drugs Advisory Committee (ODAC). The purpose of ODAC is to review the safety and effectiveness of drugs used in the treatment of cancer, as well as to make recommendations to the commissioner of Food and Drugs based on its findings. According to Dr. Mathieu, this body plays an essential role in ensuring the quality and safety of marketed and investigational drugs, ultimately protecting the patients who use them. OI