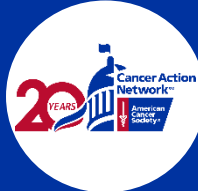




# BLACK VOLUNTEER CAUCUS FIRESIDE CHAT

## *“The Black Community is Being Left Behind – Why Aren’t They Included in Clinical Trials?”*



### WELCOME

Thank you for participating in the American Cancer Society Cancer Action Network (ACS CAN) Black Volunteer Caucus’ first virtual Fireside Chat. Today’s outstanding and dynamic speakers will discuss the Black community’s unique challenges to cancer care that can be addressed through culturally competent care and removing barriers to clinical trial enrollment. The Fireside Chat speakers will discuss how the DIVERSE Trials Act (H.R. 5030 and S. 2706) will increase participation among representative populations, including Black patients, helping to alleviate cancer-related disparities and tackle the disproportionate cancer burden communities of color and people living in under-resourced areas too often experience.

We hope you will continue to join us for future BVC events and activities and greatly appreciate your support for this important work towards reducing inequities in the Black community.

### **BLACK VOLUNTEER** ACS CAN’s Black Volunteer Caucus (BVC)



**CAUCUS**

**Ensuring Inclusion and Involvement in the Black Community**

The Black Volunteer Caucus is an all-Black volunteer led advisory group dedicated to advancing health equity and eliminating health disparities. The BVC guides ACS CAN’s work to enhance, strength, and diversify communications, messaging, partnerships, and volunteer recruitment, training, and engagement within the Black community. BVC members share a common and national focus on building a diverse structure to decreasing death and suffering from cancer specifically in the Black community and ensuring no one is disadvantaged in the fight against cancer. [fightcancer.org/BVC](http://fightcancer.org/BVC)

### **American Cancer Society Cancer Action Network (ACS CAN)**

The American Cancer Society Cancer Action Network (ACS CAN) makes cancer a top priority for elected officials and candidates at the federal, state, and local levels by empowering advocates across the country to make their voices heard. As the American Cancer Society’s nonprofit, nonpartisan advocacy affiliate, ACS CAN staff work closely with American Cancer Society experts to identify and develop evidence-based public policies that promote access to prevention and early detection, treatment, and follow-up care. ACS CAN is strictly nonpartisan and does not endorse, oppose, or contribute to candidates or political parties. The only side ACS CAN takes is the side of people facing cancer and survivors. Cancer impacts everyone, but it does not impact everyone equally. Significant disparities in cancer prevention, screening and treatment persist, meaning not every individual has an equitable opportunity to survive and thrive after cancer. ACS CAN holds a strong commitment to [addressing these disparities](http://fightcancer.org) and advancing health equity in communities nationwide. [fightcancer.org](http://fightcancer.org)





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## American Cancer Society Cancer Action Network & Black Volunteer Caucus (BVC) Fireside Chat

### AGENDA

Tuesday, June 28, 2022



*Please use the hashtag #DIVERSETrialsAct and tag @ACSCAN in your posts for this event*

- 12:00 pm**    **Welcome and Overview**  
-Faith Nyong, DNP, RN, ACS CAN ACT Lead & Black Volunteer Caucus Member
  
- 12:05 pm**    **Diversity in Clinical Trials: Cancer Care Disparities in the Black Community**  
-Michellene Davis, Esq., President & CEO, National Medical Fellowships, Inc.
  
- 12:25 pm**    **Improving Access to and Diversity in Clinical Trials**  
-Senator Cory Booker, D., New Jersey
  
- 12:30 pm**    **Removing Barriers to Clinical Trials in the Black Community Through the DIVERSE Trials Act**  
-Devon Adams, RN, MPH, ACS CAN Senior Analyst, Policy & Legislative Support – Emerging Science
  
- 12:45 pm**    **Questions and Answers**  
-Participant Pre-submitted and Live Questions
  
- 12:55 pm**    **Closing Remarks**  
-Faith Nyong, DNP, RN, ACS CAN ACT Lead & Black Volunteer Caucus Member



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### SPEAKER BIOGRAPHIES



**Michellene Davis, Esq.**, President and Chief Executive Officer, National Medical Fellowships, Inc.

Michellene Davis assumed the role of President and Chief Executive Officer of National Medical Fellowships, Inc., (NMF) in May of 2021. Founded in 1946, NMF was one of America’s first diversity organizations and remains the only national organization advancing health equity at the intersection of wealth and health. It provides scholarships to Black, Indigenous, People of Color (BIPOC) medical and health professions students underrepresented in medicine to ensure equity of access to culturally competent, high-quality healthcare.

NMF also increases the number of BIPOC clinician leaders to diversify clinical trials. 11th Annual ACS CAN National Forum on the Future of Health Care Speaker Biographies 6 Davis is named among Modern Healthcare magazine’s Top 25 Most Influential Minority Leaders in Healthcare and Becker’s Hospital Review’s 113 Great Leaders in Healthcare 2022 and Top 50 African Americans to Know in Healthcare. The National Association of Health Services Executives awarded her their 2021 Senior Health Care Executive Award.

Davis most recently served as Executive Vice President and Chief Corporate Affairs Officer at RWJ Barnabas Health, the largest academic medical center system in New Jersey and one of the largest in the nation. She founded Social Impact and Community Investment, an equity-centered, policy-led community health practice addressing the social and political determinants of health. She was the first African American in state history to serve as Chief Policy Counsel to former New Jersey Governor Jon S. Corzine, the first African American and only the second women to serve as New Jersey State Treasurer.

She was the youngest person to serve as CEO of the New Jersey Lottery and also served as a senior policy advisor in the New Jersey Department of Health and Senior Services. She co-authored Changing Missions, Changing Lives: How a Change Agent Can Turn the Ship and Create Impact, published by Forbes Books in 2020, which provides a blueprint for those committed to leading systems change within organizations. Ms. Davis began her legal career as a trial litigator, is an Honors graduate of Seton Hall University and holds a Juris Doctorate from Seton Hall School of Law. She holds Executive Education Certificates in Corporate Social Responsibility from the Harvard Business School and in Social Impact Strategy from the Wharton School of Business.

**Devon Adams, RN, MPH**, ACS CAN Senior Analyst, Policy & Legislative Support – Emerging Science



Devon Adams works on policy related to cancer research, device and drug development, and clinical trials for the American Cancer Society Cancer Action Network (ACS CAN), the American Cancer Society’s nonprofit, nonpartisan advocacy affiliate. Devon leads ACS CAN’s work to improve access to biomarker testing in cancer and expanding access to telehealth for people living with and beyond cancer.

In addition to his ACS CAN experience, Devon has practiced as a registered nurse in critical, emergency, and public health settings and has a BSN from the University of Louisiana, Lafayette and an MPH in Health Policy and Management from the George Washington University.



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### Senator Cory Booker, D., New Jersey

Cory Booker believes that the American dream isn’t real for anyone unless it’s within reach of everyone. Booker has dedicated his life to fighting for those who have been left out, left behind, or left without a voice.

Booker grew up in northern New Jersey and received his undergraduate degree from Stanford University. At Stanford, Booker played varsity football, volunteered for the campus peer counseling center, and wrote for the student newspaper. He was awarded a Rhodes Scholarship and went on to study at the University of Oxford, and then Yale Law School, where he graduated in 1997.

After graduating law school, Booker moved to Newark and started a nonprofit organization to provide legal services for low-income families, helping tenants take on slumlords. In 1998, Booker moved into the Brick Towers housing project in Newark, where he lived until its demolition in 2006. Booker still lives in Newark’s Central Ward today, where the median household income is less than \$15,000.

At 29, Booker was elected to the Newark City Council, where he challenged the city’s entrenched political machine and fought to improve living conditions for city residents, increase public safety, and reduce crime.

Starting in 2006, Booker served as Newark’s mayor for more than seven years. During his tenure, the city entered its largest period of economic growth since the 1960s. In addition, overall crime declined and the quality of life for residents improved due to initiatives such as more affordable housing, new green spaces and parks, increased educational opportunities, and more efficient city services.

In October 2013, Booker won a special election to represent New Jersey in the United States Senate. In November 2014, Senator Booker was re-elected to a full six-year term.

As New Jersey’s junior Senator, Cory Booker has brought an innovative and consensus-building approach to tackling some of the most difficult problems facing New Jersey and our country. He has emerged as a national leader in the effort to fix our broken criminal justice system and end mass incarceration, helping craft the most sweeping set of criminal justice reforms in a generation, the First Step Act, which became law in December 2018.

Booker has also worked to reform America’s broken food system, address our nation’s nutrition crisis, and end food insecurity. Booker sits on the Judiciary Committee, the Foreign Relations Committee, the Committee on Agriculture, Nutrition, and Forestry, and the Small Business Committee.



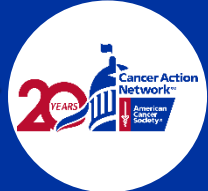
### Faith Nyong, DNP, RN, Ascension Health, ACS CAN ACT Lead, Black Volunteer Caucus Member

Faith Nyong is a Faith Community Nurse with [Ascension Mercy](#), and resides in North Aurora, Illinois. She got involved with the American Cancer Society’s Making Strides Against Breast Cancer (MSABC) 6 years ago, after becoming aware of the frightening statistics that surround African American women and breast cancer. Although African American women have a lower incidence of breast cancer, they have the highest mortality rate when compared to any other race. When she got involved with MSABC, she became dedicated to raising awareness in Fox Valley African American churches about the disproportionate effects of breast cancer. Her



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MSABC team has been successful in increasing African American participation and donations at the annual West Suburban MSABC event. She has also created a TAG-A-Sister health initiative that celebrates local African American Women that have completed their annual breast cancer screening, sends screening reminders, and assists at-risk women in receiving free mammograms.

Her pursuit to address the need for policy changes to increase health equity for African Americans, improve access to care; as well as remove barriers to cancer screenings, treatment, and life-saving cancer research trials led her to join ACS CAN. For the last 5 years has had the privilege of working as an ACT Lead with ACS CAN, have traveled to Washington, D.C. to participate in several Leadership Summit and Lobby Day events, and in 2019, she participated on a team that received national recognition for assisting with the passage of the Illinois Tobacco 21 bill. In August 2021, Faith became an inaugural and founding member of ACS CAN’s Black Volunteer Caucus, a volunteer-led advisory group that advances inclusion and involvement of the Black Community in ACS CAN’s initiatives and campaigns. In October 2021, she was a keynote panelist for the American Cancer Society’s “Fighting for Health Equity Breast Cancer Screening Forum”.

Additionally, in 2016, she was honored by Compañeros en Salud for outstanding health and wellness promotion services to Aurora’s Hispanic community. In 2018, Congressman Bill Foster presented her with the “Taking Back Our Community – Outstanding Neighbor Award”, and she also became a recipient of the Top Ladies of Distinction, Orchid Award. In 2019, to promote health and wellness, she coordinated a team that secured a 1st Place Award for the largest Chicagoland Gospel Run 5K Team, which was comprised of over 150 African Americans. In 2021, she received the City of Aurora’s Mayoral Healthcare Hero Award. She enjoyed working in the community and building partnerships to decrease health disparities.

On a personal note, she is celebrating 25 years of marriage to Lawrence Nyong and she has 3 children: Lawrence II, Lauren and Victor.



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### RESOURCES

[Take Action on the DIVERSE Clinical Trials Act](#)

*American Cancer Society Cancer Action Network*

Ask your member of congress to cosponsor the DIVERSE Trials Act (H.R. 5030 and S. 2706).

[Become a Member of ACS CAN](#)

*American Cancer Society Cancer Action Network*

Join ACS CAN and help us end suffering and death from cancer. Together, we're making fighting cancer a top priority in Congress and in every state legislature across the nation. From securing federal funding for lifesaving cancer research to ensuring every American has access to cancer screening and care, our work is saving more lives.

[Barriers to Patient Enrollment in Therapeutic Clinical Trials for Cancer](#)

*American Cancer Society Cancer Action Network (2018)*

This report serves as a resource to inform discussions and actions aimed at addressing the barriers preventing patient participation in cancer clinical trials.

[Cancer Research and Disparities. Understanding and Addressing Issues](#)

*American Cancer Society Cancer Action Network (2021)*

This report addresses the role research plays in potentially causing disparities, as well as how research can help identify and address root causes of disparities. Topics include disparities in cancer clinical trial participation, researching disparities in cancer outcomes, and cancer workforce disparities.

[The Facts On Our Fight](#)

*American Cancer Society and American Cancer Society Cancer Action Network (2022)*

A series of data briefs that talk about cancer disparities and the work ACS and ACS CAN are doing with communities, including the Black community, to advance health equity

[An Introduction to Clinical Trials – YouTube](#)

*Black Health Matters*

A comprehensive overview of clinical trials, their purpose, how they are conducted, and their impact when participant representation is diverse.

[ClinicalTrials.gov](#)

*NIH U.S. National Library of Medicine*

A database of privately and publicly funded clinical studies conducted around the world. Explore 418,463 research studies in all 50 states and 220 countries.

# ACS CAN Supports the Diversifying Investigations Via Equitable Research Studies for Everyone (DIVERSE) Trials Act H.R. 5030/S. 2706



## Overview

Clinical trials are key to advancing new standards of care that can improve survival and quality of life for people with cancer. To be successful, trials must enroll an adequate number of participants. However, patient enrollment in cancer clinical trials is an ongoing challenge, and **some groups are underrepresented**, including certain racial and ethnic groups, older adults, rural residents, and those with limited incomes.

**Cost to trial participants is often a barrier to their enrollment.**<sup>1,2</sup> For a patient, clinical trial costs involve both direct medical and ancillary (i.e., non-medical) costs. Most insurers are required to cover the direct medical or “routine costs” of treatment ordinarily administered absent a clinical trial, while trial sponsors cover the expenses for procedures or medications that are necessary only for the research study.

Patients are frequently responsible for non-medical costs such as transportation and lodging associated with trial enrollment. These ancillary costs can occur when no local trials are available and patients have to travel to distant trial sites, or when there is a need for more frequent clinic visits for additional trial-related treatment or monitoring. The additional costs can lead to disparate participation rates between high- and low-income cancer patients. **Offering to reimburse patients for ancillary costs associated with trials can increase overall enrollment and may also increase participation from underrepresented groups.**<sup>3</sup> Some trial sponsors provide financial support for ancillary costs. Those that do not often cite concerns about running afoul of federal research participant protections that could subject them to civil monetary penalties. This is despite clear guidance from the U.S. Food and Drug Administration and Institutional Review Boards that such support is acceptable.

**The bipartisan DIVERSE Trials Act (H.R. 5030/S. 2706) could increase diversity in clinical trials and make it easier for all people with cancer to participate in clinical trials by reducing their barriers to enrollment.**

## The DIVERSE Trials Act (H.R. 5030/S. 2706):

- Creates a statutory safe harbor so that patients may get financial support for the ancillary costs associated with their clinical trial participation,
- Allows trial sponsors to provide patients with technology necessary to facilitate remote participation in clinical trials, and
- Requires the Department of Health and Human Services to issue guidance on how to conduct decentralized clinical trials to improve demographic diversity.

## ACS CAN Position

ACS CAN supports the DIVERSE Trials Act (H.R. 5030/S. 2706) to ensure more patients—regardless of their economic means or their geographic location—have a chance to enroll in clinical trials.

**\$** Patients cite costs as one of the top reasons for declining clinical trial participation.<sup>1</sup>

Patients making less than \$50,000 per year are nearly 30% less likely to enroll in cancer clinical trials.<sup>2</sup>

**X** 1 out of 5 cancer clinical trials will fail due to inadequate enrollment.<sup>1</sup>

Ancillary costs associated with clinical trial participation can add to patient out-of-pocket costs and deter enrollment.

- Transportation
- Childcare
- Lodging
- Meals

<sup>1</sup> American Cancer Society Cancer Action Network. Barriers to Patient Enrollment in Therapeutic Clinical Trials for Cancer, (2016). Available at [www.fightcancer.org/clinicaltrialbarriers](http://www.fightcancer.org/clinicaltrialbarriers)

<sup>2</sup> Unger, J. M., Gralow, J. R., Albain, K. S., Ramsey, S. D., & Hershman, D. L. (2016). Patient Income Level and Cancer Clinical Trial Participation: A Prospective Survey Study. *JAMA oncology*, 2(1), 137–139. <https://doi.org/10.1001/jamaoncol.2015.3924>

<sup>3</sup> Nipp, R. D., Lee, H., Powell, E., Birrer, N. E., Poles, E., Finkelstein, D., Winkfield, K., Percac-Lima, S., Chabner, B., & Moy, B. (2016). Financial Burden of Cancer Clinical Trial Participation and the Impact of a Cancer Care Equity Program. *The oncologist*, 21(4), 467–474. <https://doi.org/10.1634/theoncologist.2015-0481>