PATIENT ADVOCACY SUMMIT:

Best Practices and Policies for Addressing the Health Needs of LGBTQ+ Cancer Patients and Survivors

Friday, December 2, 2022
NCCN Patient Advocacy Summit: 
Best Practices and Policies for Addressing the Health Needs of 
LGBTQ+ Cancer Patients and Survivors

The National Press Club, Washington, D.C. 
December 2, 2022
9:00 AM – 3:00 PM

8:30 – 9:15 AM Breakfast and Registration

8:30 AM Exhibitor Tables Open

9:20 – 9:30 AM Welcome and Introductions
Wui-Jin Koh, MD
Senior Vice President/Chief Medical Officer
National Comprehensive Cancer Network

9:30 – 10:10 AM Advancing Equity Through The CMS Innovation Center
Dora L. Hughes, MD, MPH
Chief Medical Officer
CMS Innovation Center Centers for Medicare & Medicaid Services

10:10 – 10:20 AM Break

10:20 – 10:30 AM Welcome Message
Admiral Rachel L. Levine, MD
Assistant Secretary for Health
Department of Health and Human Services
10:30 – 11:45 AM  **Breaking Barriers: Identifying and Addressing Unique Cancer Care Needs of LGBTQ+ Patients**
Moderated by Clifford Goodman, PhD
Sr. Vice President, Comparative Effectiveness Research
The Lewin Group

**Panelists:**

Bláz Bush, MEd
Executive Director, LGBTQ+ Health Program
Stanford Medicine

Paula Chambers-Raney
Stage I Colon Cancer Survivor
Advocate for Screenings in LGBTQ+ Communities of Color
Hope Coordinator, Fight Colorectal Cancer

Archana Pathak, PhD
Interim Director, Q Collective
Special Assistant, Programs and Initiatives
Associate Professor, Gender, Sexuality, and Women’s Studies
Virginia Commonwealth University

Mandi L. Pratt-Chapman, PhD
Associate Center Director for Community Outreach, Engagement and Equity
GW Cancer Center
Associate Professor of Medicine, GW School of Medicine and Health Sciences
Associate Professor of Prevention and Community Health
GW Milken Institute School of Public Health
The George Washington University

Chasity Burrows Walters, PhD, RN
Senior Director, Patient & Community Education
Memorial Sloan Kettering Cancer Center

11:45 AM – 12:45 PM  Lunch
12:45 – 1:30 PM

**Best Practices Presentations from Patient Advocates:**

**Cancer Support/Provider Training Resources**
Scout, Ph.D.
Executive Director
National LGBT Cancer Network

**Respectful and Inclusive Efforts in NCCN Guidelines for Patients®**
Tanya Fischer (she/her), MEd, MSLIS
Senior Medical Writer, Patient Information
National Comprehensive Cancer Network

**Supporting LGBTQ+ Couples with Cancer** (Pre-Recorded)
Darryl Mitteldorf, LCSW
Executive Director and Founder
Malecare
National LGBT Cancer Project

**Creating Affirming and Culturally Responsive Care for LGBTQ+ Patients**
Sean Cahill, PhD
Director of Health Policy Research
The Fenway Institute
1:30 – 2:45 PM  **Policy Solutions to Advance Equitable Cancer Care for LGBTQ+ Community**

Moderated by Clifford Goodman, PhD
Sr. Vice President, Comparative Effectiveness Research
The Lewin Group

**Panelists:**

Sean Cahill, PhD
Director of Health Policy Research
The Fenway Institute

Earl Fowlkes,
President/CEO
Center for Black Equity

Karen L. Parker, PhD, MSW
Director of the Sexual & Gender Minority Research Office (SGMRO)
National Institutes of Health (NIH)

Scout, Ph.D.
Executive Director
National LGBT Cancer Network

Ryne Wilson, DNP, RN, OCN
RN Care Coordinator
University of Minnesota Physicians

2:45 – 3:00 PM  **Wrap-up and Conclusions**

Gary Weyhmuller, MBA, SPHR
Chief Operating Officer
National Comprehensive Cancer Network
Bláz Bush, MEd

Bláz is the Executive Director of the LGBTQ+ Health Program at Stanford Medicine. He previously served as the Manager of the Office of Diversity and Inclusion's Program at the University of Colorado School of Medicine. In this role, Bláz developed customized training on DEI topics, from workplace bullying to LGBTQ+ affirming healthcare, facilitated restorative circles for students, faculty, and staff, and advised the GME residency programs on best practices for recruitment and retention of trainees. Previously, Bláz served as the Director of the LGBT Center at the University of Louisville School of Medicine, where he designed a series of annual didactic sessions and patient simulation training on LGBTQ+ affirming healthcare, and Director of Care Coordination at the Callen-Lorde Community Health Center in New York City, a 19,000-patient LGBTQ+ Federally Qualified Health Center (FQHC). Bláz also worked to triple their grant portfolio to $4 million for wrap around social support services focused on those living with HIV and individuals who are transgender or non-binary.

Bláz completed his Bachelor’s at the University of Oklahoma, majoring in theatre with a minor in psychology. He received a Professional Certificate in Restorative Justice Facilitation from the University of San Diego and completed a Master’s in Education at the University of Oklahoma.

Sean Cahill, PhD

Sean Cahill, PhD is Director of Health Policy Research at the Fenway Institute, Affiliate Associate Clinical Professor of Health Sciences at Northeastern University, and Adjunct Associate Professor at Boston University School of Public Health. Cahill serves on the Massachusetts Special Legislative Commission on LGBT Aging, and on the HIV and Aging Policy Action Coalition. He is Director of Policy for the HRSA HAB-funded 2iS Coordinating Center for Technical Assistance. An Associate Editor at LGBT Health, Cahill has authored or coauthored over 100 peer-reviewed journal articles, monographs, chapters, and books on LGBTQ+ health, LGBTQ+ public policy issues, and HIV/STI prevention and care.
Tanya Fischer, MEd, MSLIS

Tanya Fischer (she/her), Senior Medical Writer in Patient Information, joined NCCN in 2019 with a background in patient education, higher education, and public, academic, and medical libraries. Tanya is active in the field of health literacy as chair of the Pennsylvania Library Association's PA Forward® Literacies Team, and as a member of Network of the National Library of Medicine (NNLM) Region 1 Senate, the International Health Literacy Association (IHRA), and European Public Health Association (EUPHA). She has served as a volunteer for the International Union for Health Promotion and Education (IUHPE) World Conference on Health Promotion and has given presentations on diversity and inclusion in the NCCN Guidelines for Patients® to state, national, and international audiences. She brings to the table a unique perspective/combination of experiences and education with Master's degrees in Educational Leadership from Northern Arizona University and Library and Information Science from University of Wisconsin-Milwaukee. She also holds a Bachelor of Fine Arts in Painting from Arcadia University.

Recently, NCCN and Patient Information won the 2022 CPEN Excellence in Cancer Patient Education Award for its unique support of diversity, equity, and inclusion in breast cancer patient resources. More information on NCCN patient resources can be found at NCCN.org/PatientResources.

Earl Fowlkes

Earl Fowlkes serves as the President/CEO of the Center for Black Equity, Inc. (formerly the International Federation of Black Pride-IFBP). He founded the IFBP in 1999 as a coalition of organizers in the United States, Canada, United Kingdom and South Africa formed to promote a multinational network of Black LGBTQ Pride and community-based organizations. The Center for Black Equity’s mission is to work towards health equity, social equity and economic equity in the Black LGBTQ+ communities. Earl has nearly thirty years of senior management experience including stints as the Executive Director of the DC Comprehensive AIDS Resources and Education Consortium (DC CARE Consortium) and Damien Ministries, organizations that provided services to Person Living With HIV/AIDS in Washington, DC.

Earl has served as member of the National African American Tobacco Education Network; the Principal Investigator for the University of Pittsburgh School of Public Health POWER research project; was a member of the 100 Black Men of American National Health and Wellness Committee; and chaired Ryan White HIV Community Planning Councils in Jersey City and Washington, DC. He currently serves on seven non-profit Boards of Directors and Advisory Boards.
Dora L. Hughes, MD, MPH

Dora Hughes, M.D., M.P.H., is the Chief Medical Officer at the CMS Innovation Center at the Centers for Medicare & Medicaid Services. She leads the Center's work on health equity, provides clinical leadership and input on models, serves as the Innovation Center's primary liaison with medical and clinical stakeholders, and provides leadership to CMMI's clinician community. In addition, Dr. Hughes is part of the Innovation Center’s Senior Leadership Team, helping to provide enterprise-level leadership and strategic direction to the Center.

Previously, Dr. Hughes served as an Associate Research Professor of Health Policy & Management at the Milken Institute School of Public Health at The George Washington University, where her work focused on the intersection of clinical and community health, health equity, social determinants of health, healthcare quality and workforce. Prior to this role, Dr. Hughes was a Senior Policy Advisor at Sidley Austin, where she advised on regulatory and legislative matters in the life science industry. Additionally, Dr. Hughes served as the Counselor for Science & Public Health to Secretary Kathleen Sebelius at the U.S. Department of Health & Human Services. In this role, she helped implement the Affordable Care Act and provided oversight and guidance to the Public Health Service Act authorized agencies and Food and Drug Administration.

Dr. Hughes began her career in health policy as Senior Program Officer at the Commonwealth Fund, and subsequently was Deputy Director for the Health, Education, Labor, and Pensions Committee under Senator Edward M. Kennedy. She then served as the Health Policy Advisor to former Senator Barack Obama.

Dr. Hughes received a B.S. from Washington University, M.D. from Vanderbilt and M.P.H. from Harvard. She completed internal medicine residency at Brigham & Women's Hospital.

Rachel L. Levine, MD

Admiral Rachel L. Levine serves as the 17th Assistant Secretary for Health for the U.S. Department of Health and Human Services (HHS) and the head of the U.S. Public Health Service Commissioned Corps. She fights every day to improve the health and well-being of all Americans. She's working to help our nation overcome the COVID-19 pandemic and build a stronger foundation for a healthier future - one in which every American can attain their full health potential. ADM Levine's storied career, first, as a physician in academic medicine focused on the intersection between mental and physical health, treating children, adolescents, and young adults. Then as Pennsylvania’s Physician General and later as Pennsylvania’s Secretary of Health, she addressed COVID-19, the opioid crisis, behavioral health and other public health challenges.
Darryl Mitteldorf, LCSW

Darryl Mitteldorf, LCSW, is an oncology social worker. He is known for pioneering the field of LGBT psycho-oncology and founding two prominent national nonprofits, the national men's cancer patient advocacy organization, Malecare, and the world’s first LGBT cancer patient advocacy organization, the National LGBT Cancer Project. Mr. Mitteldorf is an NIH-funded investigator who has presented at numerous professional conferences and published peer-reviewed journal articles and book chapters. He has invented and holds patents on two medical devices. Mr. Mitteldorf has led over 2,000 support group meetings since 1998 and interviewed over 100 leading clinicians for Malecare's YouTube channel. Mr. Mitteldorf is leading the development of Cancer Academy, the world's first patient-focused cancer education online platform, launching in 2023.

Karen L. Parker, PhD, MSW

Karen L. Parker currently serves as Director of the Sexual & Gender Minority Research Office (SGMRO) at the National Institutes of Health (NIH). Dr. Parker was instrumental in the formation of the office in fall of 2015 and was appointed Director in June 2016. Dr. Parker is also a member of the NIH Anti-Harassment Steering Committee and serves as the co-chair of the NIH Office of the Director Equity Council. Additionally, she sits as an ad-hoc member on the Advisory Committee to the NIH Director Working Group on Diversity.

Dr. Parker is involved in several SGM-related initiatives beyond NIH. She serves as co-chair of the Sexual Orientation and Gender Identity Working Group of the Federal Committee on Statistical Methodology as well as an Executive Director for the Department of Health and Human Services LGBTQI+ Coordinating Committee.

She began her career at NIH in 2001 as a Presidential Management Fellow. Dr. Parker received her Bachelor of Arts in English from Indiana University and her Master of Social Work from the University of Michigan. She subsequently completed her Ph.D. at the University of Maryland, School of Social Work.
Archana Pathak, PhD

Archana A. Pathak, Ph.D., is a diasporic feminist, scholar and activist. Pathak examines issues of social identity from a social justice perspective and is academically trained in intercultural communication and qualitative research methods. Her work explores how we tell ourselves and each other who we are through the lens of autoethnography.

She is a former president and board member of The Conciliation Project, a non-profit theater organization that addresses issues of racism and oppression. She presented a TEDx Talk based on her scholarly work on immigration and race, titled “Embracing My Superpower: Living in the In-Between.” Pathak currently serves as the interim director of Virginia Commonwealth University’s Queer Research and Advocacy Center—the Q Collective—and as special assistant for programs and initiatives in the Office of Institutional Equity, Effectiveness and Success. She is also an associate professor in the Department of Gender, Sexuality, and Women’s Studies.

Mandi Pratt-Chapman, PhD

Mandi Pratt-Chapman, PhD is Associate Professor of Medicine for the GW School of Medicine and Health Sciences, Associate Professor of Prevention and Community Health for the GW Milken Institute School of Public Health, and Associate Center Director, Patient-Centered Initiatives and Health Equity for the GW Cancer Center. Her personal mission is to make evidence-based health care and disease prevention strategies available to more people as quickly as possible. Her research focuses on patient navigation, cancer survivorship, evidence-based cancer control, and health equity for intersectional lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) communities. She recently founded a nonprofit called Inclusivity that aims to foster dialogue and arts-based research to reduce polarization and foster inclusive perspectives to solve challenging social problems. Learn more at radicalinclusivity.net
Paula Chambers Raney

Paula Chambers Raney is a stage III colon cancer survivor that became an advocate because she does not want anyone to have to struggle as much as she did.

After her own bout with a delayed diagnosis, advocate Paula Chambers Raney is on a mission to ensure Black and gay women like herself get the diagnosis and care they need.

Paula, who overcame a bout with colorectal cancer in 2015, spoke to business leaders and government officials about her experience as a young Black lesbian, and urged policymakers to fund research on the disease and to ensure equitable access to screenings.

When she can, Paula shares her cancer story in local hospitals, at LGBTQ+ health events, with local politicians, as well as on social media.

Scout, Ph.D.

Scout is the Executive Director of the National LGBT Cancer Network and the principal investigator of both the CDC-funded LGBTQ tobacco-related cancer disparity network and Out: The National Cancer Survey. He spends much of his time providing technical assistance for tobacco and cancer focusing agencies expanding their reach and engagement with LGBTQ+ populations. Scout has a long history in health policy analysis and a particular interest in expanding LGBTQ+ surveillance and research. He has faculty appointments at both Brown University and Boston Universities’ Schools of Public Health. He is a member of the NIH Council of Councils, the Co-Chair of the NIH Sexual and Gender Minority Research Office Work Group, on the Advisory Panel for NIH’s All of Us initiative, and a U.S. Pharmacopeial Convention delegate. His work has won him recognition from the U.S. House of Representatives, two state governments, and many city governments. Scout is an openly transgender father of three, a vegetarian, an avid hiker and runner.
Chasity Burrows Walters, PhD, RN

Chasity Burrows Walters is the Senior Director of Patient and Community Education at Memorial Sloan Kettering Cancer Center. She is responsible for the vision, leadership, and strategic planning of educational initiatives that reach millions across the globe. Widely recognized for her efforts to promote health equity, Dr. Walters is an expert in health literacy and relentless proponent of using plain language. As a result of her policies, patients and caregivers around the world have free access to MSK’s extensive online library of patient education resources and materials. A longstanding advocate for the LGBTQI community, she is the Founder and Leadership Sponsor of MSK’s LGBTQI Clinical Advisory Committee and a leader in LGBTQI+ Pride, MSK’s Employee Resource Network. Dr. Walters is a member of multiple professional organizations, including the Oncology Nursing Society, the American Society of Clinical Oncology, GLMA, and is a past Chair of the Cancer Patient Education Network. In addition to awards for her leadership during her academic career, Dr. Walters received the Oncology Nursing Society Excellence in Patient and Public Education Award and the Cancer Patient Education Network’s Distinguished Service Award. She has presented and published on a range of topics related to the care of LGBTQ patients. Dr. Walters teaches LGBTQ Public Health at Rutgers University’s Edward J. Bloustein School of Planning and Public Policy.

Ryne Wilson, DNP, RN, OCN

Ryne Wilson, DNP, RN, OCN is a board-certified registered nurse deeply committed to improving equitable access to high-quality patient care. He is a trained systems thinker with extensive experience in care coordination, navigation, and healthcare leadership. He is actively involved with the Oncology Nursing Society’s Center for Health Policy and Advocacy and serves as part of the LGBTQ+ policy focus group. Dr. Wilson received his Bachelor of Science in Nursing (BSN) from Western Kentucky University and his Doctor of Nursing Practice (DNP) in Health Innovation and Leadership from the University of Minnesota. He holds certifications in Leadership, Health Care Design and Innovation, and Oncology Nursing.
NCCN Appreciates and Recognizes the Following Supporters for this Summit:

AbbVie
ADC Therapeutics
AmerisourceBergen
Amgen
AstraZeneca through its NCCN Corporate Council Membership
BeiGene, Ltd.
2seventy bio
Bristol Myers Squibb
Boehringer Ingelheim Pharmaceuticals, Inc.
Eisai Inc
EMD Serono, Inc.
EQRx
Exact Sciences
Exelixis
Foundation Medicine, Inc.
GSK
Helsinn

Heron
Incyte Corporation
Janssen Oncology
Kadmon, a Sanofi Company
Kite, a Gilead Company
Lilly
Merck & Co., Inc.
MorphoSys US, Inc.
Pharmacyclics, an AbbVie Company
Regeneron Pharmaceuticals, Inc.
Sanofi
Servier
Sun Pharma Oncology
Taiho Oncology
Upcoming Events
View the online calendar at NCCN.org/events.

Friday, March 31, 2023 – Sunday, April 2, 2023

Annual 2023 Conference
New Location! Orlando World Center Marriott • Orlando, FL
Virtual attendance available

REGISTER NOW: NCCN.org/conference

Friday, September 22, 2023 – Saturday, September 23, 2023
Hilton San Francisco Union Square • San Francisco, CA
Virtual attendance available