

## Cancer Policy & Advocacy Team (CPAT) Symposium Faculty Biographies

### Music as Care



#### **Tamara Wellons, Smith Center for Healing and the Arts**

Tamara Wellons is a vaunted, soulful vocalist whose artistry resonates in multiple realms with the vitality of the timeless definition of rhythm and blues. With two decades of experience as a recording artist, Tamara has executive produced three albums and has a profoundly diverse career working with internationally and nationally Grammy award winning DJ/Producers. Tamara is President/CEO of Her Dreams Productions, and is founder of a music with a message platform entitled Healings Grams. Her work in the Arts in Health field has brought her most treasured experiences both as a singer and as a manager of programs. Tamara manages the Artist in Residence Program for Smith Center for Healing and the Arts' at two hospitals and four cancer centers in Northern Virginia. She volunteers her time as an advocate for music creators within the membership of the Recording Academy where she serves as the Washington DC Chapter Board President.

### Advocate Panel



#### **Shelley Fuld Nasso, MPP, NCCS Chief Executive Officer**

Shelley is honored and humbled to serve NCCS and the millions of cancer survivors and their family members NCCS represents. She is a policy wonk and advocate and loves to empower cancer survivors to make their voices heard in Washington, DC and around the country. She joined NCCS in December 2012 and was named CEO in October 2013.

Prior to joining NCCS, Shelley served in leadership roles at Susan G. Komen, where she leveraged Komen's grassroots network in Washington, DC and in state capitals. There she built relationships with policymakers and partner organizations and led a team of staff and volunteer leaders to influence state budgets and legislation. Shelley has also served as Director of Community Philanthropy at The Dallas Foundation and held management positions at communications and technology enterprises. She is a graduate of Rice University and holds a Master of Public Policy from the Harvard Kennedy School. Shelley's commitment

to the work of NCCS is strongly tied to the experiences in the cancer care system of her dear friend, Dr. Brent Whitworth, a beloved physician who was diagnosed with stage IV cancer days before his 42nd birthday and who passed away 19 months later. Through Brent's experiences, Shelley witnessed the strengths and flaws of the cancer care system and embraces the notion that policy change can make cancer care better for patients and caregivers.



#### **Kimberly Bowles**

Kim Bowles is the President and founder of [NotPuttingonaShirt.org](http://NotPuttingonaShirt.org), a 501(c)(3) organization advocating for optimal surgical outcomes for women going flat after mastectomy – aesthetic flat closure (AFC) – since 2018. The organization empowers patients with tools and resources to advocate for their choice, and works with institutional stakeholders – surgeons, hospitals, insurance companies, regulatory bodies – to push for improved standard of care for AFC. Their work also includes legislative initiatives. They are currently working with Rep. Stacey Pheffer Amato on New York Assembly Bill 8537 to ensure insurance coverage for AFC services for patients in New York state. This work will directly translate to the federal level. Their next

initiative will target the Women's Health & Cancer Rights Act (WHCRA) of 1998. Kim was diagnosed with stage 3 breast

cancer at the age of 35 as a mother of two young children and has been NED since 2017. Her message is that AFC is a healthy, valid and beautiful mastectomy choice.



**Michael Holtz**

Michael Holtz is a 10-year survivor of stage-3b rectal cancer, which drives his interest in ensuring other people get preventive screenings or are not diagnosed with cancer. Michael is the Tennessee lead volunteer for the American Cancer Society Cancer Action Network (ACS CAN), a role he has held for seven years. He was previously on staff for ACS CAN and the American Cancer Society for 12 years. His advocacy experience includes working on statewide smoke free campaigns in Tennessee and Alabama; the passage of the ACA; the passage of the Removing Barriers to Colorectal Cancer Screening Act; continuing work on the Palliative Care and Hospice Education and Training Act; and ongoing work to increase federal funding for cancer research and prevention programs. Michael has met with his federal lawmakers and their staff on numerous occasions and has also advocated for Fight Colorectal Cancer during Call On Congress in 2021 and 2022. Professionally, he has experience in grassroots organizing and media advocacy campaigns.



**Nicole Bullock, MBA**

Nicole C. Bullock, MBA is the Founder & CEO of the [Nicole Cares Foundation](#). She earned a BS in Organization Management and an MBA from Purdue University. While battling Non-Hodgkin Lymphoma, God placed a calling on her life to use her cancer journey to help others, bring awareness to blood cancer, and share how He healed her body. In 2017, Nicole founded the Nicole Cares Foundation, a 501 (c) 3 nonprofit organization whose mission is to assist people affected by lymphoma, raise public awareness and funds for research, and provide support services for cancer patients. The foundation provides care packages, financial and survivor support groups, and blood drives. Nicole is dedicated to closing the health gap for African Americans who face health disparities leading to later diagnosis and death. Through her work with cancer patients and as a cancer survivor, Nicole brings a unique perspective to her advocacy work and looks forward to collaborating with other advocates.

**Achieving Cultural Humility in Medical Care**



**Lori Wilson, MD, FACS, Howard University College of Medicine**

Lori L. Wilson, MD, FACS, Fellow of the American College of Surgeons and Chief of Surgical Oncology at Howard University Hospital & Professor, College of Medicine; is an accomplished surgical oncologist, clinician scientist, mentor, and community activist. As prior General Surgery Program Director, she mentored thirty-three outstanding young surgeons. Dr Wilson completed her undergraduate and medical school training at Georgetown University, general surgery residency at Howard University Hospital (HUH) then completed a fellowship in Complex Surgical Oncology at John Wayne Cancer Institute (JWCI) and Cedar Sinai. Her first faculty position was at UConn Health as Associate Director of Surgery, Melanoma and GI Programs as well as Surgical Director of The UConn Clinical and Translational Breast Program in The Carole and Ray Neag Comprehensive Cancer Center.

Her global surgery efforts have led to 9 humanitarian missions to low resourced countries in Africa. Dr. Wilson has developed several programs at Howard University Cancer Center to serve under-represented minorities, which is a mission of hers. She received an R01 grant as well as others to aid in this mission. Dr. Wilson has been active as the Cancer Liaison Physician of the ACS as well as the CoC State Chair DC. She been Director of the monthly Howard University Cancer Center Mammoday Program for 9 years providing free breast cancer care for underinsured and uninsured patients.

Nationally, she has led the Susan G. Komen African American Health Equity Initiative and led the development of a national literacy campaign, “Know Your Girls” which was supported by newsprint, radio and national news networks. As a national surveyor for the National Accreditation Program for Breast Centers, she surveyed over 80 programs focusing on breast health with dedication to improvement of quality outcomes for patients.

Her engagement with the lay public regarding health literacy is found in magazines and newspapers including, The New York Times & NYT OpEd, Los Angeles Times, The Hill, Essence Magazine, Vogue, Better Homes and Garden. She shares her own journey in the Ken Burns’ Documentary based on the Pulitzer Prize Winner, Cancer The Emperor of All Maladies, where she was followed and eloquently helped to reshape the way the public sees cancer.

Dr. Wilson has served on the Board of Directors for the American Cancer Society, African Women’s Cancer Awareness Association (AWCAA) as well as the Advisory Board of other cancer-related organizations such as ACT for NIH.

Dr. Wilson has given over 180 academic and community lectures capped by an invitation to the White House from former President Obama to discuss healthcare disparities.

## Health Policy Outlook for 2022

Shelley Fuld Nasso, MPP (*bio previously listed*)



### **Haley Smoot, Director of Public Policy, National Coalition for Cancer Survivorship**

Haley Smoot joined NCCS in the fall of 2021 and serves as the Director of Public Policy. She is responsible for representing cancer survivors on Capitol Hill and with federal agencies and state governments to advance NCCS’s policy priorities.

Prior to joining NCCS, she worked with the Texas Health and Human Services Commission where she led and implemented critical legislative initiatives, including projects centered on CHIP, Medicaid, and the implementation of the Affordable Care Act in Texas, and provided strategic guidance and support as the Senior Policy Advisor to more than 40 social services programs. Apart from her experience in state government, she worked with the American Heart Association and Leukemia & Lymphoma Society where she spearheaded policy, advocacy, and partnership efforts.

Haley’s passion for cancer policy and advocacy stems from her own personal connection. Her father battled cancer from 2015 to 2017, and her mother was later diagnosed with cancer in 2019. As her parents’ caregiver, she witnessed first-hand the challenges of the current health system and the importance of quality cancer care.

Haley holds a bachelor’s degree in History from Rhodes College in Memphis, Tennessee and a master’s degree in Material and Visual Cultures of the Past from the University of Edinburgh in Scotland. She is currently pursuing a second master’s degree in Global Health Policy from the University of Edinburgh.



### **Anne Hubbard, MBA, American Society for Radiation Oncology (ASTRO)**

Anne Hubbard is the Director of Health Policy for the American Society for Radiation Oncology. As Director of Health Policy, Ms. Hubbard leads efforts to inform Medicare and private payer of policies that impact the practice of radiation oncology. This includes oversight of the CPT and RUC process, coding and coverage policies, as well as the development of an Alternative Payment Model for Radiation Oncology. Prior to joining ASTRO in 2014, she spent four years with the Maryland Hospital Association where she was involved with the renewal of Maryland’s All Payer Medicare Waiver. Ms. Hubbard has also worked for the State of Maryland as the Director of Governmental Affairs for the Department of Health and Mental Hygiene. She has a BA in Government and Politics from the University of Maryland at College Park and an MBA with a concentration in Finance

from Loyola University Maryland.



**Rebecca Kirch, JD, National Patient Advocate Foundation (NPAF)**

As Executive Vice President of Policy and Programs, Rebecca Kirch provides strategic focus and leadership in bringing the millions of patient and family voices NPAF and PAF represent to the forefront of national health care quality improvement efforts.

She previously worked 15 years at the American Cancer Society and its advocacy affiliate, the American Cancer Society Cancer Action Network. As the Society’s first director of quality of life and survivorship, she orchestrated the development of its national agenda addressing pain, symptoms, and distress experienced by patients, survivors, and caregivers. She created collaborative initiatives in research, programs, and advocacy for integrated palliative, psychosocial, and rehabilitation services, as well as

enhanced clinical communication skills.

Rebecca also played a leading role in planning and executing the Institute of Medicine 2015 joint workshop “Comprehensive Cancer Care for Children and Families” and the National Academy of Science, Engineering and Medicine’s Quality Care for People with Serious Illness Roundtable 2017 workshop on “Integrating Patient and Family Voices in Serious Illness Care.” She also serves as Quality of Life and Person-Centered Care’s task force co-chair for the American Congress of Rehabilitation Medicine and a board member for children’s oncology care camps.

**Integrative Oncology: Empowering through Evidence and Equity**



**Ana María López, MD, MPH, Sidney Kimmel Medical College**

Ana María López, MD, MPH, FACP, is Professor and Vice Chair of Medical Oncology at Sidney Kimmel Medical College and Chief of Cancer Services at Sidney Kimmel Cancer Center – Jefferson Health – New Jersey. Dr. López has served as an NCCS Board Member since 2021.

Dr. López joined Jefferson in 2018 from the Huntsman Cancer Institute in Salt Lake City, UT, where she was Director of Cancer Health Equality and Inclusion and served as Associate Vice President of Health Equality and Inclusion at the University of Utah Health. A board-certified Medical Oncologist, Dr. López’s clinical expertise is in women’s malignancies, integrative medicine and oncology, and telehealth.

Dr. López is President-Emeritus of the American College of Physicians, the largest medical specialty organization in the United States. Her strong commitment to health equity is reflected in her work with the American Society of Clinical Oncology as former Chair of the Health Equity Committee, and with the Association of American Medical Colleges where she serves as Member of the Steering Committee of the Group of Women in Medicine and Science. Her areas of expertise and research focus include cancer prevention, integrative oncology, and innovations in healthcare.



**Lesley Kailani Glenn**

The passion, motivation, and personal experience of living with metastatic breast cancer for the past 9 years drives Lesley’s advocacy. She partners with communities, researchers and organizations to aid the funding of research for a cure, bringing awareness to this overlooked stage of breast cancer and support to those who live daily with Metastatic Breast Cancer. With a Bachelors of Science in organizational leadership, Lesley has been actively involved in advocacy since 2015, training with the inaugural Hear My Voice Volunteer class presented by Living Beyond Breast Cancer.

She was invited back as a mentor in 2018 and awarded the Living Beyond Breast Cancer Leadership Volunteer Award in the Fall of the same year. She is the Co-Founder of the Annual Make Good Moves, Climb for a Cure ([www.climbforacure.net](http://www.climbforacure.net)), an event held annually in Southern California and Southern Oregon that funds research for a cure. Lesley

enjoys working with researchers and other stakeholders in the metastatic breast cancer field. She is a member of the

Metastatic Breast Cancer Alliance, Susan G. Komen's Advocates in Science, on the scientific advisory committee for the Love Research Army, and a consumer reviewer with the DOD-CDMRP, PCORI and Komen. She recently launched her biggest endeavor, [Project Life](http://www.projectlifembc.com) ([www.projectlifembc.com](http://www.projectlifembc.com)), which is a virtual wellness house for those living with metastatic breast cancer and their loved ones. You can follow the initiative on twitter [@projectlifembc](https://twitter.com/projectlifembc).



### **Desirée Walker, NCCS CPAT Steering Committee**

At the age of 38, Desirée was diagnosed with breast cancer, which reoccurred at 47. She serves as an advocate for patients by openly speaking about her diagnosis to audiences globally. Desirée shares her time and talent conducting outreach in the African American community to educate others about breast and ovarian cancers as well as the importance of research and participating in clinical trials.

Her goal as an advocate is to increase the likelihood that all cancer survivors and thrivers have access to quality health care and quality of life after a diagnosis. Through research advocacy, she reminds the research community that science cannot truly advance without participant diversity, especially those burdened by disease. Through SHARE's Side by Side Program, Desirée trains medical students and physicians on how to deliver disappointing news. She also volunteers with NCCS, NCI CIRB, Society of Integrative Oncology SWOG and Young Survival Coalition. She seeks resources to train communities on research and legislative advocacy.

## **Resiliency and Legacy**



### **Alique Topalian, PhD, MPH, University of Cincinnati**

Alique was diagnosed with cancer (AML) for the first time at four years old. This experience inspired her to obtain a Master's in public health and a Ph.D. in Health Promotion and Education, which she earned in March 2020. Alique always knew she wanted to have her research associated with oncology and survivorship. Since she is an early career researcher, she started her research in the mental and behavioral health arena and focused on programming for psychosocial behaviors. In March of 2021 she relapsed with AML, the first person to ever relapse after 22 years. During her time in active treatment, she used every opportunity to network, participate in psychosocial programming of all forms, and educate herself on resources available to patients through all stages of treatment. She aims to find her way into the oncology survivorship research realm.

## **Telling Your Story in 140 Characters**



### **Andrew Conte, PhD, Center for Media Innovation, Point Park University**

Andrew Conte, Ph.D., serves as founding director of the [Center for Media Innovation](#) at Point Park University. He writes the [Pittsburgh Public Editor column](#) at [NEXTpittsburgh](#). Previously, he worked as an investigative journalist, and he has authored several nonfiction books, including the forthcoming *Death of the Daily News* (September 2022, University of Pittsburgh Press).

Andrew previously worked as an investigative reporter at the Pittsburgh Tribune-Review, where he won numerous national, state and local awards. The Pennsylvania Society of Professional Journalists and the Press Club of Western Pennsylvania each has recognized Andrew with its top award four times. The Scripps Howard Foundation [honored Andrew with the William Brewster Styles Award](#) for outstanding national business and economics reporting.

Andrew's book, [The Color of Sundays](#), explores the role of race in the National Football League and examines how the Pittsburgh Steelers identified undervalued players at historically black colleges and universities. The Independent Book

Publishers Association recognized the book with a [Silver Benjamin Franklin Award](#). Prior to that, Andrew authored [Breakaway](#), a bestseller about how the Penguins hockey team built a championship franchise and a new arena. He also has written [All About Roberto Clemente](#), a children’s book about the Pirates outfielder and Puerto Rican native.

Andrew holds degrees from [Columbia University’s Graduate School of Journalism](#) and [Dickinson College](#), as well as a [Ph.D. in Community Engagement from Point Park University](#).

You may find more at [AndrewConte.com](#).

## Improving Doctor/Patient Communications Workshop



### **Thomas J. Smith, MD, Johns Hopkins Medicine**

Dr. Smith is an oncologist and palliative care specialist with a lifelong interest in better symptom management and improving access to high quality affordable care. As an oncologist he specialized in comprehensive multi-disciplinary breast cancer for 25 years. With the late Dr. Chris Desch he helped start the Rural Cancer Outreach Program (RCOP) of Virginia Commonwealth University’s Massey Cancer Center. This brought state of the art cancer care including clinical trials and palliative care to five rural hospitals in Virginia. The RCOP improved care dramatically, saved patients millions of travel miles, and ensured that indigent patients could receive care near their home. As an oncologist, he worked to remove the financial incentives for giving chemotherapy, and to standardize guidelines for care.

With Patrick Coyne and others, he helped start the Thomas Palliative Care Unit and Program at VCU-MCV in the late 1990s, one of the first academic palliative care programs in the country. He and colleagues showed that palliative care improved symptoms, allowed patients and families to choose the care they wanted, did not cost more than usual care, and even improved survival.

Currently, he is the Director of Palliative Medicine for Johns Hopkins Medicine, charged with integrating palliative care into all the Johns Hopkins venues. The PC consult service sees over 1500 new patients a year, and a research agenda with “Scrambler Therapy” for chemotherapy induced neuropathy, neuromyelitis optica spectrum disorder pain, and central pain; palliative care for patients on Phase I drug trials; palliative care for patients undergoing Whipple procedures; and auricular point acupressure for cancer pain, among others.

Dr. Smith has been recognized in “Best Doctors in America” for many years and is a Fellow in the American College of Physician, the American Society of Clinical Oncology and the American Academy of Hospice and Palliative Medicine. In 2015, he received the ACS Trish Greene Award for “outstanding research that benefits cancer patients and their families”, and in 2018 was recognized as a “Visionary in Palliative Care” by AAHPM. In 2019 he received the Project on Death in America (PDIA) Palliative Medicine National Leadership Award, and the Walther Foundation-ASCO award for excellence in supportive oncology. In 2020 he received the Ellen Stovall Award from the National Coalition of Cancer Survivors that recognizes individuals, organizations, or other entities who demonstrate innovation in improving cancer care for patients in America. He has published over 450 articles, editorials and reviews, and helped write the test questions for the ABIM hospice and palliative medicine exam.