Webinar 3: Functional Outcomes of Sickle Cell Disease — The Whole-Person Experience

Panelist Biosketches

Session 1: Functional Outcomes in Sickle Cell Disease

Payal C. Desai, MD is an Associate Professor at Levine Cancer Institute at Atrium Health, where she is Director of the Sickle Cell Enterprise. Dr. Desai completed her fellowship in hematology and oncology at University of North Carolina at Chapel Hill, Chapel Hill, NC where she pursued disease specific training in sickle cell disease on a T32 training award. She is board certified in Internal Medicine and Hematology. She worked at the Ohio State University for almost 10 years as the director of sickle cell research and program. Under her leadership, she led the only joint commission recognized Sickle Cell Center of Excellence in the country. Dr. Desai has authored or co-authored over 40 papers primarily in the field of sickle cell research. Dr. Desai holds professional memberships with the ASH and is the current president of the Sickle Cell Adult Provider Network (SCAPN). She has been the peer reviewer, principal investigator, and adjudicator on multiple sickle cell clinical trials and studies.

Dr. Kelly Harris is an Assistant Professor of Occupational Therapy, Surgery (Public Health Sciences), and Education at Washington University in St. Louis, School of Medicine, and leads the Health Equity, Opportunity, and Education Research Lab. She is also a licensed Speech-Language Pathologist, and has provided clinical services in medical, educational, and community settings for over 20 years. Dr. Harris' research agenda examines the interdependence of chronic disease, opportunity, and educational outcomes for youth in communities impacted by systems of oppression, as well as environmental justice, and the use of dissemination and implementation science to advance health and educational equity in school and community settings. She is particularly interested addressing the complications of sickle cell disease and asthma, and the unidentified impacts these conditions have on achievement and opportunity for Black youth.

Dr. Eboni Lance is a neurologist and medical director of the Sickle Cell Neurodevelopmental Clinic and Research Center at Kennedy Krieger Institute (KKI). She is an associate professor in the Department of Neurology at the Johns Hopkins (JH) School of Medicine. Dr. Lance completed undergraduate studies at Princeton University, her MD at Medical University of South Carolina, and her PhD in clinical investigation at JH School of Public Health. She completed residency in pediatrics at Childrens Hospital Los Angeles and residency in neurodevelopmental disabilities at KKI. Dr. Lance's research interest is in people with sickle cell disease and neurodevelopmental issues.

Dr. Lakeya McGill is an Assistant Professor of Medicine in the Division of General Internal Medicine at the University of Pittsburgh. As a licensed clinical-community psychologist, she has provided behavioral health services to adults with sickle cell disease (SCD). Her long-term career goal is to improve pain care for this population by developing, testing, and implementing effective psychosocial and multi-level interventions at the patient, clinician, healthcare system, and policy levels. Dr. McGill's research led to her selection for the inaugural cohort of the NIH/HEAL National K12 Clinical Pain Career Development Program through the University of

Michigan. Her current K12 project examines how intersectional stigma (i.e., biases based on multiple identities and characteristics) affects pain outcomes in adults with SCD. Her research identifies multi-level risk factors, protective factors, and treatment targets, laying the groundwork for interventions that advance high-quality pain care.

Jean L. Raphael, M.D., M.P.H. is Division Chief for Academic General Pediatrics, Professor of Pediatrics, and Vice Chair for Clinical Affairs in the Department of Pediatrics at Baylor College of Medicine and Texas Children's Hospital. He is a nationally recognized health services researcher with a focus on health equity and improving systems of care for children with sickle cell disease. He is the Immediate Past President of the Academic Pediatric Association, Council Member for the American Pediatric Society, and member of the American Academy of Pediatrics Committee on Child Health Financing. He is a past appointee of the Lieutenant Governor to the Texas Health Disparities Task Force and recipient of a Meritorious Service Award from the Texas Health and Human Services Commission.

Session 2: Sickle Cell Disease and Daily Life: Lived Experience

Omini Ewah is the Co-Founder of OBIA Naturals, an award winning hair care brand previously featured in Forbes Magazine and was nominated “Small Business of the Year” in 2020 by Amazon. Omini is a registered nurse, a “Sickle Cell Warrior” and an active member of the Massachusetts Sickle Cell Association.

Golda Houndoh is a global health professional, patient advocate, and public health researcher committed to advancing health equity, particularly for individuals living with sickle cell disease (SCD). Born in Togo, West Africa, and diagnosed with SCD at age one, her lived experience navigating fragmented healthcare systems drives her passion for patient-centered care, policy reform, and systemic change. As Program Associate II at PCORI, Golda manages a clinical research portfolio focused on maternal health, SCD, and chronic disease disparities, ensuring community-driven research. Previously, as Program Director at Cayenne Wellness Center, she led a HRSA-funded initiative to improve healthcare access and outcomes for SCD patients across California through designing transition models, provider education, and advocacy. Golda is also a certified community doula with Birth in Color DMV, providing reproductive health support to women of color. Through her research, advocacy, and programmatic work, she remains dedicated to "bridging research and advocacy to drive impactful, patient-centered, sustainable solutions.

Vesha Jamison is a Sickle Cell Account Manager with the American Red Cross for the state of South Carolina. Vesha came to the Red Cross in August of 2021 … a former Community Health Worker and an avid leader and supporter in the Sickle Cell arena. Her passion in advocacy began in 2010 after the birth her son, Dreylan, who was diagnosed with sickle cell disease, type SS. He is now a high school freshman and joins her as she works tirelessly to spread awareness. In her 10 years of community outreach and persistent efforts to sound the alarm and bring Sickle Cell Disease to the forefront, she conjunctively works with other moms, sickle cell warriors, advocacy partners, medical professionals, and community organizations. Vesha and her son have been able to make an impression nationally by being featured on the CBS Evening News with Nora O’Donnell and Good Morning America, in addition to various other local news, radio, podcasts, and events and serve as the founders of their own advocacy organization. At the Red Cross, Vesha uses her experience to build long term partnerships by educating others on sickle cell disease and the importance of blood donation in the black and African American community. Her personal passion for creating awareness and making an impact is what motivates her to continue this marathon. Her motto is "They fight every day, and so should we."

Josh Lewis is a sculpture artist, woodworker, maker, DIYer, and designer. He is also a Sickle Cell Warrior and advocate.

April Ward-McGrory is a sickle cell patient and advocate for those living with sickle cell disease.