

This year, we are celebrating World Sickle Cell Awareness Day (June 19, 2022) and Juneteenth in collaboration with National Black Nurses Association and the Sickle Cell Disease Coalition (SCDC) by honoring the life and legacy of renowned nurses, providers, researchers, advocate, and community leaders.



**DOMINIQUE BULGIN, PHD, RN**

Dr. Dominique Bulgin is a nurse scientist and Assistant Professor at The University of Tennessee, Knoxville College of Nursing. She is passionate about health promotion in sickle cell disease, domestically and globally. Her research focuses on promoting health equity by improving health outcomes for individuals with sickle cell disease through disease self-management and reducing the influence of health-related stigma, discrimination, and racism. She has experience implementing health promotion interventions for sickle cell disease into practice and community settings. Dr. Bulgin also participates in the National Black Nurses Association Sickle Cell Subcommittee.



**CORETTA M. JENERETTE, PH.D., RN, AOCN, CNE, ANEF, FAAN**

Shortly after entering the nursing profession, Dr. Coretta Jenerette was exposed to the plight of adults with SCD and quickly learned that the same rules for pain management did not apply to this population. Because the health care system is not willing (or able) to provide adequate care for individuals living with SCD, her research focuses on improving self-care management for individuals with SCD. In 2020, she was selected by Sickle Cell 101 as the National Sickle Cell Advocate of the Year. She is the Treasurer for the International Association of Sickle Cell Nurses and Professional Associates. In addition, Dr. Jenerette is the Co-Chair of the National Black Nurses Association Sickle Cell Subcommittee.



**NADINE MATTHIE, PHD, RN, CNL**

Dr. Nadine Matthie is an Assistant Professor in the Nell Hodgson Woodruff School of Nursing at Emory University in Atlanta, Georgia. She is a nurse scientist who aims to alleviate chronic pain and enhance self-management among adults living with the sickle cell through research funded by agencies including the National Institute of Nursing Research and the National Heart, Lung, and Blood Institute, published in national and international sources. Dr. Matthie also works to improve sickle cell awareness and care as a member of the International Association of Sickle Cell Nurses and Professional Associates, Chair of the National Black Nurses Association's Sickle Cell Disease Working Group, and member of the Sickle Cell Disease Coalition's Sickle Cell Trait Task Force. Currently, she is developing non-pharmacological, home-based, patient-centered interventions incorporating technology and biopsychosocial approaches to help adults with sickle cell cope with their pain.



**DORA CLAYTON-JONES PH.D. RN CPNP-PC**

Dr. Dora Clayton-Jones is an assistant professor at Marquette University in the College of Nursing and an adjunct faculty member for the Medical College of Wisconsin-Clinical and Translational Sciences Institute. Using community-based participatory research and qualitative research methods, she partners with the community and recipients of interventions to advance health and health care equity for adolescents and young adults living with sickle cell disease. Dr. Clayton-Jones is president of the International Association of Sickle Cell Nurses and Professional Associates (IASCNAPA). She serves on the American Society of Hematologists Community Advisory Board-Wisconsin Sickle Cell Disease Clinical Trials Unit. She also serves on the Versiti Blood Center of Wisconsin Community Center Advisory Board. In addition, Dr. Clayton-Jones is a member of the National Black Nurses Association Ad Hoc Committee on Population Health Sub-Committee on Sickle Cell.



**ANGELA ADJETEY APPIAH, PHD (c), DNP, MPH, RN, COA, FAACM**

Dr. Angela Adjete Appiah is a member of the National Black Nurses Association's Population Health Sickle Cell Disease Working Group and member of the Sickle Cell Disease Coalition's Sickle Cell (SCDC) Trait Task Force, in addition to the SCDC Clinical, Global Issues and Access to Care Working Groups. Her interest resides in implementing disease prevention, health promotion, and clinical trials for sickle cell.



**SELENA WEBSTER-BASS, MPH**

Selena Webster-Bass is a nationally recognized health equity advocate. She has held leadership roles with several Jacksonville-based institutions, including the University of Florida (UF) Health Jacksonville, where she was Community Medicine Director for the pediatrics and family medicine residency programs, Shands Jacksonville/Nemours Children's Clinic, where she served as Manager of the Pediatric Sickle Cell Clinic, and the Jacksonville System of Care Initiative, where she led mental health literacy, multicultural engagement, and cultural competence educational efforts. In 2016, Ms. Webster-Bass launched Voices Institute, a training, consulting, and research group focused on advancing and promoting health equity efforts that address physical, mental, and emotional well-being needs in families, communities, organizations, and systems.



**CHARLEEN JACOBS, MS, RN, ANP-BC**

Charleen Jacobs is an Adult Nurse Practitioner who practices at Mount Sinai Hospital's Adult Program for Sickle Cell Disease. While she has 16 years of experience in the nursing profession, in the last seven years, she has become an expert in sickle cell care as a nurse practitioner. Charleen is passionate about caring for sickle cell patients, which has impacted her daily clinical work. Ms. Jacobs has co-authored publications about sickle cell disease and co-chaired a pain resource nurse program to ensure patients receive appropriate pain management while hospitalized for a pain crisis. She is currently a Ph.D. in nursing candidate at Adelphi University College of Nursing and Public Health. Her dissertation focuses on the experiences of adults living with sickle cell disease.



**YVONNE M. CARROLL, RN, JD**

Yvonne Carroll is the Director of Patient Services in Hematology at St. Jude Children's Research Hospital. She is a researcher, a lawyer, and a nurse. Ms. Carroll has managed SCD grant awards from the NIH, the Department of Health and Human Services, and numerous other organizations. Her work has impacted the care of individuals with sickle cell disease locally, nationally, and globally. Ms. Carroll has collaborated to develop an evidence-based SCD nursing curriculum, implement an intensive 4-day SCD Nursing Bootcamp, and successfully establish a newborn screening program and an under 7 sickle cell clinic with partners in Kano, Nigeria. She has project-managed sickle cell grants for over 20 years and published numerous SCD articles in peer-reviewed journals. She has been involved in SCD community-based participatory research for more than 15 years and is a true advocate for SCD warriors.



**THERESA CARTER, MS, RN**

Theresa Carter has contributed tremendously to sickle cell work. She joined the ROC City Sicklers in 2020, an advocacy group for children and families living with sickle cell. Since then, Ms. Carter has spearheaded many activities on their behalf, including securing speakers of interest for educational in-services and devising a mental health and wellness resource list with information on the crisis and suicide hotlines, hospitals, and centers open to assist with mental health concerns and a teen crisis center; supporting sickle cell blood drives quarterly and donating blood at least 4-5 times per year, facilitating the donation of \$500 of grant money from RBNA to Pharmacy/Social Work at a local hospital to assist with the purchase of medications for those with sickle cell; joining the Sickle Cell Advocates of Rochester to increase community awareness; and educating and advocating for individuals with sickle cell disease and their families.



**CHEEDY JAJA, PHD, MPH, MSN, PMHNP-BC, FAAN**

Dr. Cheedy Jaja's interest in social justice, health disparities, and improving health outcomes in historically marginalized and vulnerable populations such as those with sickle cell disease (SCD) drives his research, clinical, and advocacy initiatives. As a clinician and health science researcher, he noticed with dismay the unsettlingly high under-five mortality rates associated with SCD in sub-Saharan Africa even though standard public-health care packages, including pre-test counseling and carriers for sickle cell hemoglobinopathy, are available and in use in middle-and high-income countries over the past 30 years. Dr. Jaja's professional partnerships and research initiatives in the West African nation of Sierra Leone are efforts to reduce this global health disparity gap. Additionally, Dr. Jaja is one of only a few nurse scientists prepared to use pharmacogenetics strategies in pharmacotherapy for SCD.



**TRUDY TCHUME-JOHNSON, MSW, LSW**

Trudy Tchume-Johnson, MSW, LSW, is the Hematology Social Work Manager and Newborn Screening Coordinator at the Children's Hospital of Philadelphia (CHOP). She has supported CHOP's Comprehensive Sickle Cell Center for two decades, offering support services to over 1,000 children living with SCD in their system. Ms. Tchume-Johnson is passionate about promoting community-based advocacy that leads to global change. With her team at CHOP, Ms. Tchume-Johnson has developed a wealth of educational materials for school personnel and caregivers of students living with sickle cell to manage unique needs and requirements that may arise throughout the school year. She also participates in the Pediatric Hospital Sickle Cell Collaborative and Sickle Cell Disease Coalition (SCDC).



**TITILOPE FASIPE, MD, PHD**

Dr. Titilope Fasipe is Co-Director of the Texas Children's Sickle Cell and Thalassemia Program and Assistant Professor of Pediatrics in Hematology/Oncology at Baylor College of Medicine in Houston, TX. As a pediatric hematologist and individual living with sickle cell, Dr. Fasipe has a unique perspective on the medical, social, and economic needs of individuals living with sickle cell and is passionate about public health strategies that curb the psychosocial barriers and health complications faced by community members. Dr. Fasipe has been repeatedly appointed to sickle cell-related advisory committees of the Texas Department of State Health Services and currently serves on their Newborn Screening Advisory Committee and Sickle Cell Task Force. Her professional memberships include the American Academy of Pediatrics; the Heartland-Southwest Sickle Cell Disease Network; the American Society of Hematology (ASH), where she serves on the Quality Measure Oversight Subcommittee as well as the Technical Expert Panel for sickle cell disease quality measures; and the American Society of Pediatric Hematology/Oncology (ASPHO), where she is the current Vice-Chair of the Hemoglobinopathy Special Interest Group. Learn more about Dr. Fasipe by following her on Twitter (@DrTitiFasipe) and listening to ASH's new podcast, "[Bringing Sickle Cell Disease to Life.](#)"



**BETTY PACE, MD**

Dr. Betty Pace is a Professor of Pediatrics and Francis J. Tedesco Distinguished Chair of Pediatric Hematology/Oncology at Augusta University. She joined the faculty at Augusta University in the Department of Pediatrics in 2010 and served as Director of the university's Pediatric Comprehensive Sickle Cell Program until 2021, providing subspecialty medical services to over 700 children with sickle cell disease. Currently, Dr. Pace provides leadership for a NIH-funded basic/translational research laboratory focused on studies related to globin gene regulation and the discovery of drugs that induce fetal hemoglobin for treating sickle cell disease. Parallel to her research efforts, since 1994, she has trained over 100 young scientists at the high school through junior faculty levels. Additionally, she directs an NHLBI-funded training opportunity: Program to Increase Diversity for Individuals Engaged in Health-Related Research (PRIDE). Her career was recently celebrated in the American Society of Hematology (ASH) podcast, "Bringing Sickle Cell Disease to Life"; to learn more about her work for the SCD community. Listen to the series [here](#).



#### **WALLY R. SMITH, MD**

Dr. Wally Smith is the first recipient of The Florence Neal Cooper Smith Professor of Sickle Cell Disease, the second African-American female chair in the United States. He also serves as the Vice-Chairman for Research of the Division of General Internal Medicine and is the former Scientific Director of the Center on Health Disparities at Virginia Commonwealth University. Dr. Smith is an experienced implementation scientist and an expert in clinical and health services research in sickle cell disease. He has authored over 100 publications and served as an investigator on over 50 externally funded grants and contracts, including principal investigator on 26 federal or foundation-funded grants and contracts. Dr. Smith has served as the Principal Investigator (PI) of the Pain in Sickle Cell Epidemiology Study (PiSCES, R01 HL 64122), the largest and most detailed adult cohort study of sickle cell pain, which changed the clinical understanding of SCD pain in adults and led to an NIH Request for Proposals on the Neurobiology of Pain in Sickle Cell Disease. Additionally, since 2012, he has been PI of likely the first-ever randomized controlled trial of implementation science in SCD, Start Healing in Patients with Hydroxyurea (SHiP HU, R18HL112737). Dr. Smith is also the host of the American Society of Hematology's (ASH) first podcast dedicated to sickle cell: "[Bringing Sickle Cell Disease to Life.](#)"



#### **CLAYTON ANDREWS, MS, LPC**

Clayton Andrews is a Licensed Professional Counselor living with sickle cell disease who has offered community-based mental health services for over a decade. He is passionate about mentoring and promoting mental health for individuals living with sickle cell, particularly young men. Mr. Andrews' counseling practice emphasizes mindfulness, cognitive behavioral therapy, and strengths-based approaches to building self-esteem, autonomy, and resilience. He is certified in the Wellness Recovery Action Plan (WRAP) for mental health wellness, recovery, and maintenance and is also a member of the Walden University Psi Chi Chapter. Outside of his counseling practice, Mr. Andrews serves as an active leader within the Sickle Cell Community Consortium, a community-based organization led by and for people impacted by sickle cell, and the Sickle Cell Disease Coalition (SCDC), an alliance of over 100 organizations united to conquer sickle cell.



#### **LAKEIA BAILEY, PHD**

Dr. Lakeia Bailey is a sickle cell disease advocate, educator, research scientist, and founder and president of the Sickle Cell Community Consortium (SCCC). Diagnosed with sickle cell disease at age three, Dr. Bailey has become a passionate advocate for those living with rare diseases and is committed to serving as a voice of encouragement and empowerment within the sickle cell community. Despite the devastating symptoms of sickle cell, Dr. Bailey was determined to complete her educational goals, earning a Bachelor's degree in Biochemistry and Molecular Biology in 2001 and a Doctorate degree in Molecular Hematology and Regenerative Medicine in 2012. She was one of the founding board of directors for the Family Advocacy Coalition for the Empowerment of the Sickle Cell Disease Community (FACE of SCD) and the founding vice president of Sickle Cell Warriors, Inc., serving as science advisor for both. After her doctorate training, Dr. Bailey founded and began working as the Executive Director of the Sickle Cell Community Consortium, a coordinated network of sickle cell community-based organizations (CBOs), patient and caregiver advocates, community partners, and healthcare/research advisors collaborating to identify, prioritize, develop and execute solutions for patient-identified needs and gaps within the sickle cell community. Dr. Bailey also acts as a contract consultant with bluebird bio, sits on the Research Advisory Board for the Foundation for Sickle Cell Disease Research, and has served as a patient engagement expert with Pfizer Pharmaceuticals.



#### **MICHAEL R. DEBAUN, MD, MPH**

Dr. Michael DeBaun is a Professor of Pediatrics and Medicine at Vanderbilt University School of Medicine, JC Peterson Endowed Chair, and founder and director of the Vanderbilt- Meharry Sickle Cell Disease Center of Excellence. For over 25 years, his research on sickle cell disease has led to fundamental changes in understanding the clinical epidemiology, pathogenesis, and treatment of strokes and silent strokes in children and adults with sickle cell disease. He has been the principal investigator or co-leader of eight NIH or foundation-funded controlled clinical trials designed to prevent strokes in children or adults with sickle cell disease in North America, Europe, and Nigeria. Dr. DeBaun was elected to the National Academy of Medicine (2009). Based on his significant contribution to advancing the care of children and adults with sickle cell disease, he received the prestigious international Ernest Beutler Prize and Lecture in Clinical Science from the American Society of Hematology (ASH) in 2014, as well as a Lifetime Achievement Award from the Stanford University Medical School in 2019. Dr. DeBaun's career highlights are also featured in ASH's new podcast series, "Bringing Sickle Cell Disease to Life," which is currently available to stream [here](#).