NATIONAL ACADEMIES Sciences Engineering Medicine

Webinar 2: Pain Management and Sickle Cell Disease

Panelist Biosketches

Session 1: Living with Sickle Cell Disease

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.

Teanika Hoffman is the Founder and Executive Director of the Sickle Cell Coalition of Maryland—a dedicated Sickle Cell warrior, passionate advocate, dynamic orator, and compassionate humanitarian.

Dr. Carolyn Rowley is the Founder and Executive Director of the Cayenne Wellness Center and Children’s Foundation founded in the year 2000, whose mission is To increase the quality of life for individuals diagnosed with sickle cell disease in California by ensuring expert, unbiased, and comprehensive care. This mission is part of a broader vision of (1) a medical system that effectively addresses the unique needs of individuals with sickle cell disease and (2) patients who are empowered and equipped to advocate for themselves. Dr Rowley also founded The Machao Orphanage Foundation, an orphanage located in Makueni, Kenya, in 2005. Where there is peace, music, art, beach, waterfalls, and sun, you will find Dr. Rowley enjoying a few of her favorite things. Her faith is what has sustained her, makes her whole, and daily orders her steps.

Session 2: Pain Management in Sickle Cell Disease

Dr. Wally R. Smith is the Florence Neal Cooper Smith Professor of Sickle Cell Disease at VCU. He is best known as the Principal Investigator of PiSCES, (R01 HL 64122), Pain in Sickle Cell Epidemiology Study, the first and largest daily pain diary cohort of adults with SCD. PiSCES first highlighted that chronic SCD pain affects over half of patients (Smith WR et al, Ann Intern Med 2008). In 16 publications, PiSCES first related daily SCD pain to ED and hospital use, body location, gender, HRQOL, alcohol use, depression/anxiety, catastrophizing, somatization, and coping. This led to an NIH Request for Proposals on the Neurobiology of Pain in SCD, to replication in Europe (van Tuijn CF, et al. Am J Hematol. 2017) and Brazil, and to published consensus definitions of acute SCD pain (Field JJ, et al. J Pain. 2018), and chronic SCD pain (Dampier et al. J Pain. 2017). It demonstrated three SCD pain prevalence/severity phenotypes (Bakshi N, et al. Pain. 2022). Dr. Smith also co-led the NIH-funded IMPROVE trial (1U10HL083732), comparing two alternative opioid PCA dosing strategies. His DHHS committee published the first National Pain Plan. He is VCU site PI for the SCD Treatment Demonstration Program Regional Collaborative for the North East. He has twice served on the NHLBI SCD Advisory Committee. He is PI of perhaps the earliest randomized controlled trial of implementation science in SCD (R18HL112737). He is an expert on the PhenX Toolkit panel to define SCD pain research batteries. He is a member of the Multidisciplinary Work Group overseeing the HEAL initiative, in response to the opioid epidemic. He was co-chair of the July 21-22, 2021 NIH Workshop, Approaches to Effective Therapeutic Management of Pain for People With SCD, an NIH-wide (7 ICs and Centers) Workshop leading in part to this RFA-AT-

24-001. Dr. Smith is a Co-Investigator and Steering Committee Member of the PCORI SCD treatment implementation project HSRP20181364 whose major outcome is VOE visits. Dr Smith is a Co-investigator and core advisor on UG3/UH3 multi-site SCD RCT of behavioral/ integrative therapy, Peer suppoRt for adolescents and Emerging adults with Sickle cell pain: promoting ENgagement in Cognitive behavioral thErapy (PRESENCE), PI Jonassaint, Charles, 1UG3HL165839-01A1. Dr. Smith has 40-years of leadership and experience in SCD. He is on the Board of the Foundation for SCD Research, a member of the American Society of Hematology and a long-time mentor of early-stage clinical investigators. His past programmatic funding includes mentorship of physicians and researchers from diverse backgrounds

Daniel Sop is a distinguished figure in the field of Biomedical Engineering, celebrated for his groundbreaking contributions at the intersection of technology, healthcare, and research. With over 15 years of technical and computational expertise and more than a decade of dedicated involvement in healthcare data management, Sop has solidified his role as a trailblazer in advancing medical science and patient care.

A graduate of Old Dominion University in Norfolk, Virginia, where he earned his Bachelor of Science degree, Daniel laid the foundation for a career defined by innovation and impact. His academic journey continued with a Master of Science in Biomedical Engineering from Virginia Commonwealth University (VCU) in Richmond, Virginia, where he delved into cutting-edge research that would shape his professional trajectory.

Currently completing his doctoral degree in Biomedical Engineering at VCU, Daniel's research focuses on understanding the complex interplay between pain, brain hemodynamics, and cognitive function in individuals with Sickle Cell Disease (SCD). His work seeks to unravel the mechanisms linking cerebral blood flow, pain sensitivity, and fluid cognition using advanced neuroimaging techniques. Through this, he aims to develop models that not only enhance our understanding of SCD but also pave the way for innovative interventions to improve patient outcomes. As the Senior Research Scientist within the Division of General Internal Medicine at VCU, Daniel spearheads several government and privately funded grants dedicated to advancing SCD research. His work extends to the field of neuroscience, where he employs magnetic resonance imaging to investigate how SCD impacts brain function and its downstream effects on pain perception and cognitive abilities. Daniel's exceptional contributions to the field have been widely recognized. In 2016, he was selected as one of only nine participants to complete the prestigious DC I-Corps program, an initiative designed to expedite technology transfer and foster innovation. His expertise has also fueled the development of mobile-based applications for pain monitoring in SCD patients, a project aimed at identifying patterns in pain and opioid use to provide actionable insights for clinicians and patients alike.

Most recently, Daniel was named a fellow in the NIH-funded Pittsburgh Intensive Training in Hematology Research (PITHR) program, reflecting his commitment to advancing hematology research and fostering diversity in the biomedical field.

At the heart of Daniel's work is a relentless aspiration: to develop evidence-based tools and models that enhance our understanding of pain and cognitive functioning in SCD, ultimately transforming the landscape of patient care. By synthesizing clinical insights with advanced technological methodologies, Daniel's work exemplifies the potential of biomedical engineering to address some of medicine's most pressing challenges.

As he continues to push boundaries and inspire future generations, Daniel Sop remains a luminary in the field, driving progress and hope in the realms of biomedical research and patient care.

Dr. Amanda Brandow is The Alexander J. & Anita L. Costigan Chair - Blood Disorders & Cancers, a Professor of Pediatrics, and the Director of the Comprehensive Sickle Cell Disease

Clinical and Research Program at the Medical College of Wisconsin. As a physician-scientist, Dr. Brandow provides comprehensive care for children and adolescents living with sickle cell disease and conducts clinical/translational research focused on the pathophysiology, assessment, and treatment of acute and chronic pain in individuals with sickle cell disease. Dr. Brandow's research has been continuously funded by the NIH and other foundations since 2008. She was a past recipient of an NIH/NHLBI K23 Award, an American Society of Hematology (ASH) Scholar Award and currently serves as PI on an NIH/NHLBI R01 and an NIH/NINDS R61/R33 HEAL award and MPI on an NIH/NHLBI U01. Dr. Brandow has been instrumental in facilitating sickle cell disease research and clinical care at the national level and served as Co-Chair for the development of the ASH Sickle Cell Disease Research Priorities, Chair of the working group for acute and chronic pain research as part of these research priorities, and she served as Chair of the development of the published ASH evidence-based guidelines for the treatment of acute and chronic pain in individuals with sickle cell disease. Dr. Brandow currently serves as Chair of the ASH Sickle Cell Disease Scientific Research Team as part of the ASH Research Collaborative. Dr. Brandow continues to advocate at the national level for comprehensive sickle cell disease pain management and has served on the US Department of Health and Human Services Pain Management Best Practices Inter-Agency Task Force and has consulted with the Centers for Disease Control and Prevention in the context of sickle cell disease pain management.

Dr. Carroll is an internationally recognized expert in the multidisciplinary management of complex and high utilizing patients with sickle cell disease (SCD). After completing his graduate medical training at Washington University in St. Louis, he completed residency in the Johns Hopkins Department of Psychiatry and Behavioral Sciences. Thereafter he was a fellow in the Behavioral Pharmacology Research Unit, studying the behavioral pharmacology of opioids. Upon leaving the fellowship, he joined faculty as an associate medical director of Addiction Treatment Services, a leading addiction treatment center at Johns Hopkins Bayview Medical Center. In 2007, he assumed his current role in the Sickle Cell Center for Adults, combining his interests in chronic pain, opioid pharmacology, and the care of complex patients. He attends in the Department of Psychiatry's Pain Treatment Program, an intensive multidisciplinary treatment program for patients with refractory chronic pain or abnormal illness behavior. He has published a number of peer-reviewed papers on SCD pain and treatment utilization, in addition to his earlier work in behavioral pharmacology and addiction treatment. Along with the multidisciplinary team of the Johns Hopkins Sickle Cell Center for Adults, he has been consulted regionally and internationally regarding management of chronic pain, psychiatric illness, and treatment utilization in SCD.

Dr. Lara Zador is an anesthesiology-trained pain specialist at Henry Ford Health in Detroit, MI. She currently serves as the Director of the Comprehensive Sickle Cell Pain Clinic. Research interests include chronic pain management in sickle cell disease, high-impact chronic pain and centralized pain.