NATIONAL ACADEMIES Sciences Engineering Medicine

Webinar 1: Hospitalization and Sickle Cell Disease

Panelist Biosketches

Session 1: Living with Sickle Cell Disease

Tristan Lee was diagnosed with sickle cell disease (SCD) in 1983 at the age of 6 months. Because not much was known about SCD the doctor who diagnosed him told his mother and grandmother that he wouldn't live past 20. However, being a family of faith, they trusted in the lord understanding that God has the final say, which has gotten him to now living well with SCD Cell at age 41 years. It was a very interesting road getting to this point. At the age of 9 he was admitted for a routine sickle cell crisis. The next thing he remembers is waking up in the ICU having suffered a stroke in the right side of his brain which paralyzed him on the left side of his body. He had to relearn how to walk, talk, and use the bathroom again on his own. He was completely different physically. People were constantly looking at him and making fun of him because of the stroke. Realizing that people were looking at him, he figured he would give them something to look at, which was my talent. He got his first acting role at age 11. When he was on stage, he realized people were still looking at him and talking about him. Only now they were talking about his talent. At 14 he began modeling school. Doing runway helped him with his balance and posture, while acting helped him with his speech and pronunciation. He graduated the acting and modeling school at the top of his class. Today, Tristan is a professional model and actor, and he has a fashion line for SCD called DiVo Stars. He also is a professional patient advocate for the Sickle Cell Disease Association of America (SCDAA) and Sick Cells. He had the opportunity of being the National Organization for Rare Disorders (NORD) Rare Disease Day Hero in 2020. Representing the SCD community nationally and internationally, he was featured on WebMD in a wonderful article about Sickle Cell that has been seen around the world. Spreading Sickle Cell Disease Awareness is a passion of his just as fashion and acting are. Tristan hopes to do much more as the years go on and until there is a universal cure for Sickle Cell Disease.

Christelle Salomon is a sickle cell warrior who has undergone a successful stem cell transplant. She is dedicated to reforming medical education and healthcare delivery to enhance the well-being of sickle cell patients. Presently, she serves as the Health Policy and Education Analyst at UCSF Sickle Cell Center of Excellence (SCCoE). In this role, she leverages social media to empower SCD warriors, caregivers, and advocates.

Sharee Turpin is a patient and advocate for Sickle Cell Disease. As a graduate of Newhouse at Syracuse University, she is a journalist who seeks out the stories no one wants. Her passions are for the arts, the healthcare industry and occasionally will find a story on how both collide. She currently works as a Patient Navigator at Golisano Children's Hospital in Rochester, New York, supporting children and families affected by Sickle Cell Disease to improve their patient experience.

Nikia K. Vaughan is a passionate advocate for healthcare equity with a diverse background in both clinical and community health. Currently, she serves as the Executive Director of the Maryland Sickle Cell Disease Association, where she leads efforts to improve the quality of life for individuals living with sickle cell disease through advocacy, education, and support services. Previously, Nikia worked at Johns Hopkins University as the Sickle Cell Communications

Coordinator and Transition Community Health Worker, under the tutelage of Dr. Sophie Lanzkron and Dr. Lydia Pecker. In these roles, she contributed to advancing sickle cell disease awareness and supported patients in navigating their care transitions.
In addition to her healthcare work, Nikia is a licensed esthetician and entrepreneur, using her expertise in beauty and wellness to empower individuals to feel confident and cared for. Nikia's dual commitment to community health and entrepreneurship reflects her passion for making a tangible difference in the lives of others, both within and outside of the clinical setting.

Teonna Woolford was born and raised in Baltimore, Maryland. Since birth, she has overcome many battles in her fight against Sickle Cell Anemia. A true warrior at heart, Teonna has recovered from numerous challenges including, but not limited to, excruciating pain crises, bilateral hip replacements, and a failed bone marrow transplant that resulted in the side effect she feared most, infertility. When searching for both educational and financial resources for fertility preservation, Teonna was taken aback by the lack of information related to women with Sickle Cell. For far too long, the Sickle Cell Community has faced tremendous disparities and have had to prioritize survival over quality of life, allowing other areas of importance, such as reproductive health, to be overlooked. To combat this, Teonna, alongside two physicians devoted to the cause; John Hopkin's Dr. Lydia Pecker and CHOP's Dr. Kim Smith-Whitley, founded the non-profit organization Sickle Cell Reproductive Health Education Directive (SC RED). SC RED is a collective of Sickle Cell warriors, providers, caregivers, and other key thought leaders advocating for high-quality sexual and reproductive care through awareness, education, advocacy, and various levels of support. With an intimate understanding of the realities of those impacted by Sickle Cell Disease, Teonna has served on several working groups for the National Institutes of Health (NIH), and the National Heart, Lung, and Blood Institute (NHLBI). Teonna has also published with the American Society of Hematology (ASH). She has been successful carrying her mission and message to schools, churches, and The White House; bringing her face-to-face with former First Lady, Michelle Obama, Dr. Ben Carson, and the late civil rights activist and humanitarian, Congressman John Lewis. In October 2021, Teonna made history as the first patient to give the Charles F. Whitten Memorial Lecture alongside her mentor, Dr. Kim Smith-Whitley. While Sickle Cell has been a large part of Teonna's life, she does her best not to let it define who she is. In her spare time, she enjoys reading, writing, cooking (therefore eating), shopping, watching movies, keeping up with current events, and most of all, spending time with her family. She has always been active in her church and seeks to put God first in her life. Like many in the Sickle Cell community, Teonna is determined to not only live but to thrive.

Session 2: Hospitalization in Sickle Cell Disease

Mary Hulihan is a Health Scientist in the Blood Disorders Surveillance and Epidemiology Branch of the Division of Blood Disorders and Public Health Genomics at CDC, where she has been participating in activities related to sickle cell disease and thalassemia surveillance since 2008. Currently, she is the project officer for the Sickle Cell Data Collection program, a surveillance system that is active in 16 states throughout the U.S.

Caroline Freiermuth is an Associate Professor of Emergency Medicine at the University of Cincinnati. She is a founding member of the Emergency Department Sickle Cell Care Coalition and is currently the Immediate Past Chair of the organization. Dr. Freiermuth has been involved in quality improvement work regarding the emergency department management of sickle cell disease since 2011. She served as co-chair for the development of the American College of Emergency Physicians point-of-care tool to guide emergency department care for SCD. She has

a passion for educating others about sickle cell disease, raising awareness about the significant morbidity and mortality, and advocating for healthcare systems and staff to improve care for this patient population. Dr. Freiermuth is actively involved in sickle cell research with hopes to contribute to the evidence that will support best practices for managing sickle cell disease, allowing for an improved and more consistent experience for patients.

Ruchi Doshi graduated from Johns Hopkins University School of Medicine ('17) and the Bloomberg School of Public Health ('16) prior to completing a combined residency in Internal Medicine-Pediatrics at Duke University ('21). She is now an Assistant Professor at Duke University and serves as a combined Medicine-Pediatrics hospitalist where she cares for young adults with childhood onset chronic conditions including individuals with sickle cell disease. She has a particular interest in the inpatient pediatric to adult healthcare transition process.

Titilope Fasipe, MD, PhD is Co-Director of the Sickle Cell and Thalassemia Program at Texas Children's Hospital and Assistant Professor of Pediatrics in Hematology/Oncology at Baylor College of Medicine in Houston, Texas. She received her Bachelor of Science from the University of Texas at Arlington and graduated from the combined MD-PhD program at the University of Texas Medical Branch. She then completed her pediatric residency at Cincinnati Children's Hospital Medical Center and her pediatric hematology/oncology fellowship at Baylor College of Medicine and Texas Children's Hospital. Dr. Fasipe is involved in community and policy efforts aimed at improving health outcomes in sickle cell disease. Further, she has the unique perspective of relating to and understanding the need for education, community awareness, support, and medical care as she is a pediatric hematologist as well as an individual with sickle cell disease. Dr. Fasipe has been repeatedly appointed to advisory committees of the Texas Department of State Health Services and currently chairs their 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), ASH Research Collaborative, and the American Society of Pediatric Hematology/Oncology. She receives funding from HRSA and NIH for projects related to sickle cell disease care, treatment, and data collection.