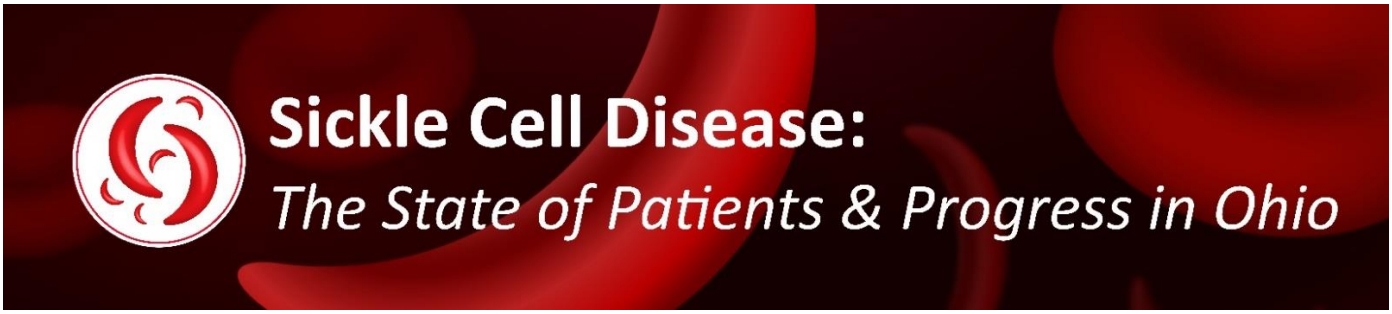


OHIO STATEHOUSE PANEL HIGHLIGHTS CHALLENGES & POSSIBILITIES FOR PEOPLE LIVING WITH SICKLE CELL DISEASE

Experts share perspectives on living with a complex disease,
and efforts in Ohio to advance new therapies
April, 2022

Two Ohio mothers with the same chronic health condition have had much different experiences.

One, 35, married with a baby, has had regular medical care most of her life and works fulltime as executive director of a nonprofit agency. She has not been hospitalized for her disease in 10 years. The other, 41, married with two kids, works part-time but can't afford a $3,500-a-month copay to manage her disease. She requires hospitalizations as many as 200 times a year that each cost thousands of dollars.

The women live with sickle cell disease (SCD), a genetic disorder that occurs in about one of every 365 Black or African American births. SCD also affects persons who are Hispanic American as well as from Central and South America and the Caribbean, according to an annual report from the Ohio Department of Health (ODH). Attributed to a mutation in hemoglobin DNA, SCD causes anemia, infections, stroke, tissue and organ damage, intense pain, and premature death.

A recent event at the Ohio Statehouse presented a panel discussion of medical providers, advocates and a patient who discussed the struggles of Ohioans with this hereditary disease. The program, "Sickle Cell Disease: The State of Patients & Progress in Ohio," highlighted advances in therapies and continuing challenges for patients from infancy through adulthood who battle this painful blood disorder. Eddie Pauline, President & CEO for BioOhio moderated the discussion.

SCD: Patient challenges, treatment innovation

Dr. Susan E. Creary, MD, an associate professor of pediatrics and a physician in the Hematology/Oncology/BMT Clinic at Nationwide Children's Hospital in Columbus said SCD is an invisible disease that affects no two people in the same way. She said it is a costly condition that can require high co-payments from insurance coverage and for medical treatments.

While there is no universal cure for SCD, there are promising new therapies emerging that can greatly improve the quality of life for SCD patients, making the difference between their ability to reach educational, professional, and personal goals or living every day as a captive of their disease. However, accessing newer therapies that could keep the 41-year-old mother who Nurse Practitioner Santina Ciarallo described during the Statehouse event, out of the hospital is

“virtually impossible” because of a prohibitive co-pay. Ms. Ciarallo works with University Hospitals Seidman Adult Sickle Cell Team.

Advocates for people living with SCD are joining other patient and medical groups to support public policy proposals aimed at reducing high out-of-pocket costs for advanced medicines.

In Ohio, children’s hospitals in Akron, Dayton, Cincinnati, Cleveland, Columbus, and Toledo, as well as regular hospitals and health systems offer SCD care for children and adults. In addition, some Ohio hospitals and their research divisions are leading efforts to discover new therapies for SCD treatment.

At the Sickle Cell Center at Cincinnati Children's Hospital Medical Center, researchers are conducting studies and trials including gene therapy investigations, to discover better treatment and possibly cures for SCD. Nationwide Children’s Hospital in Columbus also provides comprehensive treatment for SCD as well as discovery efforts through sickle cell anemia clinical studies. The Sickle Cell Anemia Center at University Hospitals Rainbow Babies & Children’s Hospital in Cleveland are conducting several active research studies to develop groundbreaking new therapies for SCD.

State of Ohio has strong SCD network

Nurses, doctors, researchers, and advocates are passionate about possibilities for their patients and appreciative of the $800,000 in funding from ODH for sickle cell disease care coordination, outreach education and training, counseling, and newborn screening, as detailed in the latest annual report for 2020. ODH works through six regions to cover the state, and Dr. Creary called Ohio’s network of SCD teams “probably the strongest in the country.” But research grants for SCD treatment and possible cures is much less than for other comparable diseases, Dr. Creary said.

Almost 3% of babies born each year in Ohio test positive in sickle cell screenings. In state fiscal year 2019, 3,444 had the sickle cell trait carrier and another 181 had the disease. The ODH data showed 80% of newborns with confirmed tests were Black or African American, which present additional challenges to successfully treating SCD, because of healthcare inequities and racial discrimination.

SCD advocates work to improve access to care

According to Annie Ross-Womack, executive director of Ohio Sickle Cell and Health Association Inc. in Columbus, much of the work of her statewide nonprofit for more than 60 years “comes from a denial of services . . . We still have issues of people going into ERs and being judged by the color of their skin,” Ms. Ross-Womack said.

One bright spot is $9.5 million awarded over 12 years (2014-2026) for Sickle Treatment & Outcomes Research in the Midwest (STORM), a region including Ohio with an estimated 15,000 SCD patients, said Lisa M. Shook, administrative director of the Cincinnati Comprehensive Sickle Cell Center and an assistant professor at Cincinnati Children’s Hospital Medical Center. The STORM demonstration project works with providers, patients and their families to improve access to care and achieve better outcomes for children and adults with SCD in the Midwest.

The STORM initiative includes more than 30 projects underway including research on how SCD affects a patient's brain, heart, kidneys, and eyes; and efforts to improve diagnosis through genome typing, and a look at stigma and bias in caring for SCD patients, Ms. Shook said.

Habiba Bankston: living successfully with SCD

Putting a powerful face on what is possible for SCD patients, Habiba Bankston described her lifelong journey to live successfully with SCD since diagnosis as an infant. Her family moved to Columbus from Brooklyn to access life-changing care available at Nationwide Children's Hospital when she was 14. Before that move, Ms. Bankston said she was typically hospitalized four or five times a year. Since diagnosed with a silent stroke at 17 – sadly common for SCD patients – Ms. Bankston has undergone monthly blood transfusions that keep her healthy and have prevented other strokes.

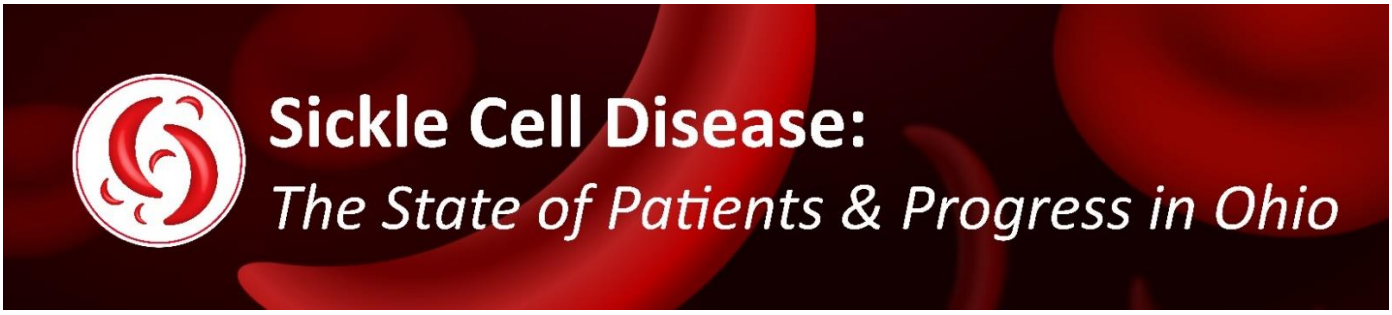
"When you look at me, you can't tell that I'm sick or I have a disease…. I'm doing incredibly well," said Ms. Bankston, now 35 and with an eight-month-old son. She is executive director of Dress for Success Columbus and wife of Columbus City Councilman and Gladden Community House CEO Nick Bankston.

Ms. Bankston said blood donations are critical to the health of people living with SCD and she encourages everyone to be active blood donors in their communities.

Ohio legislators provide perspective

Rep. Mary Lightbody, D-Westerville, brought an appreciation for the challenges of SCD to the Statehouse as a former schoolteacher, recalling how one of her students struggled with the intense pain of his disease. Sometimes legislators' best ideas come from the public, she said.

Rep. Thomas West, D-Canton, encouraged those who seek better care for sickle cell patients to let legislators know what resources are needed. "You guys are the message. Go out and advocate," West urged.



Sickle Cell Disease: The State of Patients & Progress in Ohio
March 22, 2022 -- Moderator: Eddie Pauline, President & CEO, BioOhio

Panel Participants:

- Welcome remarks, **Rep. Thomas West** (D-Canton)
- **Susan Creary, MD, MSc,** Nationwide Children's Hospital
- **Dee Meier RN, BSN, ACN,** Sickle Cell Nurse Pediatric Hematology and Oncology Rainbow Babies and Children's Hospital
- **Santina Ciarallo NP,** UH Seidman (Adult) Sickle Cell Team
- **Lisa M. Shook DHPE, MA, MCHES, CCP** Administrative Director Comprehensive Sickle Cell Center at Cincinnati Children's Hospital Medical Center & Asst. Professor University of Cincinnati Dept. of Pediatrics
- **Annie Ross-Womack,** Executive Director Ohio Sickle Cell and Health Association
- **Habiba Bankston,** SCD Patient and Executive Director, Dress for Success Columbus