



# SICKLE CELL NEWS IN TENNESSEE

MAY 29, 2023

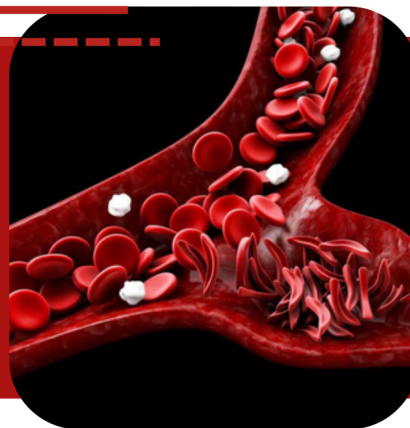


## CDC SITE VISIT

SCDC-TN was honored to host Mary Hulihan, DrPH, for a CDC site visit in March. She joined us for a day of break-out groups, presentations, and discussions about future funding. The day was capped by a dinner at St. Jude, hosted by Global Pediatric Medicine. As director of the SCDC program, Dr. Hulihan offered feedback on our efforts and goals for the next funding cycle.

## SCDC-TN, 2023-28 FUNDING CYCLE

The SCDC-TN team, led by Dr. Matthew Smeltzer, spent March and April compiling documents, making plans, sketching out time lines, and working on a budget in preparation for the submission for a 5-year renewal of funding for our SCDC program. The proposal was submitted to the CDC on May 11.



## CONFERENCE PRESENTATION

Allison Plaxco, MPH, will present "Understanding the Burden of Sickle Cell Disease in Rural and Urban Tennessee" on June 25 at the Academy Health Annual Research Meeting. Because there is no national or state registry for people living with SCD, and little epidemiologic (continued on p. 2)

*Health Academy presentation, continued*

information, the team sought a better understanding of the burden of SCD on warriors and families. Using de-identified data from TennCare and Tennessee's newborn screening program, they sought to better understand health outcomes and patterns of healthcare use among a group of 3,559 warriors represented in the data. Their goal was to identify gaps in care so that access to care, quality of care, and ultimately life expectancy could be improved.



The team found an uneven distribution of SCD cases in Tennessee, with 66.5% of people living in the urban areas of Nashville (Davidson County) and Memphis (Shelby County) at the time of birth. Overall, 8.3% of warriors in this observational study lived in rural areas and 91.6% in urban areas. In rural areas, 50.51% of individuals with SCD are under the age of 30, compared to 58.14% in urban areas. Additionally, in the rural setting, 67.68% live in a county with no practice locations of physicians who are trained in hematology-oncology, compared to only 3.10% who live in urban settings.

The results of this analysis show that more than 65% of sickle cell warriors living in rural areas of TN do not have hematology-oncology trained providers practicing in their counties. Thus, there is a critical need to improve access to care so that these individuals can be treated by specialists in sickle cell disease, rather than physicians who lack that training.

This study has brought the team closer to understanding the demographics and patterns of healthcare use for sickle cell warriors in TN. Many questions remain, of course, and the team plans to explore many areas, should they receive CDC funding for the next 5 years. Among many other goals, the team will seek a better understanding of health disparities and inequities in SCD and the effect of social determinants of health so that the data can lead to better policy decisions to improve access to care, resource allocation, service implementation, and educational efforts.

---

**Additional authors:** Judy Dudley; Ayesha Mukhopadhyay, MPH; Jane Hankins, MD, MS; Amanda J. Young, PhD; Meredith Ray, PhD; Vikki Nolan, DSc, MPH; Robert Davis, MD, MPH; Yvonne Carroll, JD, RN; Jamie Whartenby, MPA; Matthew Smeltzer, PhD; and William Cooper, MD

## TEAM MEMBER HIGHLIGHT: ALLISON PLAXCO, MPH



Allison Plaxco, MPH, is a doctoral candidate at the University of Memphis' School of Public Health, concentrating in Biostatistics. Mentored by Dr. Matthew Smeltzer and Dr. Meredith Ray, Allison has focused her work on the epidemiology of sickle cell disease and non-parametric clustering methods. She has been involved in SCDC since she began her PhD studies. She supports the SCDC team by managing data, tracking key milestones related to the project, and conducting analyses. Allison has also had experience teaching introductory statistics to undergraduate students at the University of Memphis and has supported the Shelby County Health Department's COVID-19 Response Unit with statistical analysis and research projects since late 2020. Her dissertation focuses on novel non-parametric methods for clustering individuals based on grouped data constructs, which she plans to apply to data related to sickle cell disease. Allison plans to graduate in May 2024

## PARTNER HIGHLIGHT: SCD NURSES BOOTCAMP



As front-line workers, nurses are in an opportune position to prevent life-threatening SCD complications through early detection and education; however, SCD education is lacking and often non-existent in nursing schools. The Sickle Cell Nursing Train the Trainer Bootcamp addresses the critical need for nurses to provide quality nursing care to people with SCD. The first bootcamp was held in April 2022 at the University of TN Health Sciences Center (UTHSC); the second was

this past April. The program is a collaboration between the UTHSC, College of Nursing; St. Jude Children's Research Hospital, Department of Hematology; and The International Association of Sickle Cell Nurses and Professional Associates. It is funded by an ACCEL grant from the Global Blood Therapeutics Foundation, UTHSC, and SJCRH. Yvonne Carroll, JD, RN, one of our SCDC investigators, is instrumental in planning and operating the bootcamp. (ACCEL grants are awarded through the GBT Foundation's Access to Excellent Care for Sickle Cell Patients program.

The bootcamp is an intensive 5-day course that teaches nurses to understand, recognize, and act appropriately in high-risk situations for people with SCD. For the first bootcamp, pre and post-tests demonstrated statistically significant improvement in participants' SCD knowledge. The second bootcamp was held April 17-21 and was expanded to include the train the trainer model so nurses could return to their institution and teach other nurses thereby leveraging the impact of the bootcamp. All expenses are paid for nurses to attend. Past bootcamp participants attended from across the US as well as Ghana, Sierra Leone, Trinidad, Tobago, and Ontario. The next bootcamp will be held October 30 to November 2023. To apply go to <https://www.iascnapa.org/copy-of-about-us>.



## UPCOMING EVENTS



### Juneteenth Family Empowerment Day Celebration

June 1, 10 am – 3 pm  
Ed Rice Community Center  
2935 N. Watkins, Memphis  
For more information:  
Yvonne Carroll,  
[yvonne.carroll@stjude.org](mailto:yvonne.carroll@stjude.org)



### Sickle Cell Awareness Day at the University of Memphis

Sept. 13, 2023  
Information Fair and Lunch and Learn  
University Center  
For more information:  
Mandy Young,  
[ajyoung@memphis.edu](mailto:ajyoung@memphis.edu)



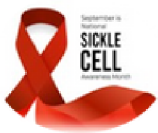
### World Sickle Cell Day

Juneteenth, June 19, 2023  
For more information:  
<https://www.sicklecelldisease.org/get-involved/events/awareness-month-and-world-sickle-day/>



### Mark Walden Sickle Cell 5K Walk

Sept. 16, 2023  
Court Square Park  
62 N. Main St., Memphis  
For more information:  
[officetn@sicklecelltn.org](mailto:officetn@sicklecelltn.org)



### Sickle Cell Awareness Month

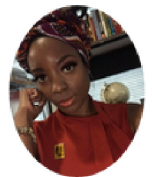
September 2023  
For more information:  
<https://www.sicklecelldisease.org/get-involved/events/national-sickle-cell-awareness-month/>

## OUR WARRIOR TEAM MATES

Each issue, we will highlight some of the warriors or caregivers on the SCDC-TN team. April McGrory and Tabatha Marmon have been contributing their insights and expertise for a long time. They are both experienced SCD advocates and have spoken to health-care providers, policy makers, educators, and fellow warriors. They are vital members of our communication team.



April McGrory



Tabatha Marmon

**To list SCD events in TN, contact:**  
**Dr. Amanda Young**  
[ajyoung@memphis.edu](mailto:ajyoung@memphis.edu)

### Sickle Cell Fact

Blood transfusions emerged as a treatment for SCD complications in the 1960s.

### Martin Luther King, Jr:

*Of all the forms of inequality, injustice in healthcare is the most shocking and inhuman.*