Sickle Cell Awareness Newsletter- Spring -

May 2023

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# **Virginia Sickle Cell Awareness Newsletter**





# **Highlights**



 Miles Thomas, MD, Candidate-Class of 2024, at Virginia Tech Carilion School of Medicine and colleagues presented <u>Characterizing Knowledge and Perceptions Towards P-Selectin</u> <u>Inhibitor Therapy and its Use in Sickle Cell Disease Patients and</u> <u>Providers</u> at the American Public Health Association's annual meeting last November 2022. The project aims to explore the intersection of newly approved drugs for Sickle Cell Disease (SCD) with the known challenges of accessibility and stigma faced by patients and their families. During the conference, they presented an analysis identifying the demographic and clinical

characteristics of SCD patients who had received crizanlizumab (Adakveo) based on de-identified health record data from the TriNetX research database. *Pictured: Miles Thomas, MD Candidate* 

• On Saturday, November 12, 2022, the Fredericksburg Area Sickle Cell

Association, Inc. celebrated its 50<sup>th</sup> anniversary of service to the community.

• The Inova Adult Sickle Center established a Patient/Family Advisory Board and held its first meeting on December 5, 2022.

• Four bills were filed for the 2023 General Assembly session regarding sickle cell disease. The bills did not make it out of the assigned subcommittees for further approval.

- <u>HB 2084</u>
- <u>HB 2085</u>
- <u>HB 2086</u>
- <u>HB 2094</u>

• The Unity Ride 4 Sickle Cell Committee honored Ms. Florence Neal Cooper-Smith at the Black History Museum on March 18<sup>th</sup> for Women's History Month. She was honored for her constant commitment toward finding a cure for sickle cell disease.

• Christy Murray, RN, MSN, CPNP, CPHON, certified pediatric hematology/oncology nurse and coordinator for the Pediatric Comprehensive Sickle Cell Program at UVA Children's, was nominated and selected as a 2023 American Red Cross, Central Virginia Chapter, Health Care Hero awardee. Christy is recognized for her work with sickle cell patients and her partnership with the American Red Cross. Congratulations, Christy!

Pictured: Christy Murray, Sharon Jones (Healthcare Hero and Blood Drive Coordinator @ UVA



*Transfusion Medicine Services), Alexis Innis (American Red Cross Account Manager and nominator)* 

• The Sickle Cell Collaborative (SCC) in the southwest region of Virginia shared several success stories with VDH. Many of the stories, like the one below, highlight the strength of comprehensive care programs and the extraordinary work programs

are doing to enhance the quality of life for individuals living with sickle cell disease.

Fifty-seven -year-old female called the SCC with vaso-occulusive crisis (VOC). Medcom contacted and the patient was instructed to go to Roanoke Memorial Hospital's (RMH) ER. Within 10 minutes of registering in the ED, she was placed in a room, and MSO4 was given 62 minutes after arrival. Received the following text from this patient on 2/24: "Thank you so much, Karen. I am so happy to have met you and thankful that you are trying to make things better for people with Sickle Cell Anemia. I'm glad you're on my team."

Kudos to Karen Marable, FNP, Brittany Belcher, BSW, and Dr. Venuto-Ashton, M.D.!

### Conferences, e-Learning, and Events

- The Foundation for Sickle Cell Disease Research is now accepting abstract and manuscript submissions for their June 2023 Hybrid Annual Symposium. The submission deadline is May 5, 2023. Learn more <u>here</u>.
- 14<sup>th</sup> Annual Unity Ride 4 Sickle Cell, RVA May 6, 2023
  The registration fee to ride your motorcycle from Zion Baptist Church in Petersburg, VA to Second Baptist Church on Broad Rock Boulevard in Richmond, VA is \$35.
  Everyone Is invited to attend Second Baptist to observe the rider's arrival.
- Reproductive Health in Individuals with Sickle Cell Disease: From Gaps to Solutions Hybrid Workshop

NHLBI will be hosting a hybrid workshop, Reproductive Health in Women and Girls with SCD: Gaps to Solutions, on May 11-12, 2023. Learn more <u>here</u>.

 Spring 2023 Sickle Cell Disease/Educator/Counselor Certification Program May 15-18, 2023 | Mobile, AL

The Sickle Cell Disease Association of America – Mobile Chapter, Inc. will host its Spring 2023 Sickle Cell Disease Educator/Counselor Certification Program starting Monday, May 15, 2023, through Thursday, May 18, 2023, in-person at the Hilton Garden Inn – Downtown, Mobile, AL 36602. **Deadline to register for the training is Friday, May 5, 2023.** Learn more <u>here.</u>

• Sickle Cell Disease: Improving the Quality and Continuum of Acute and Ambulatory Patient Care

The Physicians' Education Resource, LLC is offering an online Continuing Medical Education (CME) activity for healthcare professionals. The training activity will discuss best practices related to the care of patients with SCD. <u>Learn more here.</u>

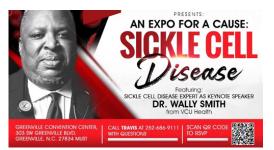
#### Save the Dates

• The Robinson's Sickle Cell Foundation Presents: An Expo for A



Cause: Sickle Cell Disease Featuring Keynote Speaker Dr. Wally Smith June 9, 2023 | 8am-4pm | Greenville Convention Center: Greenville, NC

National Heart, Lung, Blood Institute (NHLBI) Annual Sickle Cell Disease Meeting



August 14-16, 2023 | Bethesda, MD or virtual The annual meeting brings together SCD investigators, practitioners, patients and advocates to discuss ongoing clinical trials, new developments and to network.

North Carolina's 11<sup>th</sup> Annual Sickle Cell Conference September 8-9, 2023 | Virtual

#### Florence Neal Cooper Smith Fundraiser and Awareness Walk, September 16, 2023 | 9am-12pm | Dorey Park

The Finding a Cure Together for Sickle Cell (FACTS) Committee will host a 5K walk to raise awareness about sickle cell disease. The proceeds will benefit the Florence Neal Cooper Smith Sickle Cell Professorship.

### **Share Updates**

Interested in sharing updates in the newsletter? Email Shamaree Cromartie at <u>Shamaree.cromartie@vdh.virginia.gov</u>

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