Statewide Steering Committee on Services for Adults with Sickle Cell Disease

Meeting Summary
Date: December 8, 2021
Time: 3 pm-5 pm

Location: Online

Committee Members Present: Lanzkron, Sophie; Williams, Rudolph; Callahan, Charles; Brown Gay, Virginia; Law, Jennie; Callahan, Chuck; Derek Robertson; Fixler, Jason; Campbell, Andrew; Martin, Abbie

Committee Members Absent: Fitzgerald, Shantia; Francis-Gibson, Beverley; Pecker, Lydia; Riley, Crystal; Strawberry, Dyshokia; Taylor, James; Williams, Paul; Nnake, Ijeoma; Baker, Francine; Buttler, Camile

Committee Co-Chairs: Sophie Lanzkron and Derek Robertson

Committee Staff Present: Monika Piccardi

Guest Present: Jed Miller, Bill Picher, Mike Phillips and Dawayn Bryant

The Steering Committee meeting was called to order at 3:07 pm.

Ground rules (meeting etiquette) were reviewed with the committee by Derek Robertson.

Monika Piccardi informed the committee of the recent MDH network security incident. Services are currently offline out of an abundance of caution. Additional information will be provided as it comes available.

Meeting roll call was conducted.

The Committee reviewed the last two meeting minutes. The minutes were not able to be approved due to not having a quorum of the steering committee for official business.

Workgroup updates
A. Access to care in Prince George’s County
   Derek Robertson mentioned that the workgroup has not officially met but a lot of work has been done related to Prince George’s County. Sophie Lanzkron explained the major goals of the grant funding for the Prince George’s County region, including improving access to high quality care for people living in Prince George’s County and not having to travel outside of the county, enhancing resources available in the Capital Region by adding in advanced practice providers to do primary care in that clinic and establish the clinic as a medical home for people with sickle cell disease (SCD). They are also enhancing the Infusion Clinic at the UM Capital Region Medical Center which is opening April 2022, using a hub and spoke model, which is a recommended
model. The Health Equity Resource Community (HERC) Pathways to Health Equity Grant will provide extra resources to be able to provide children with much needed transition resources. Resources will be focused on Prince George’s County. Dr. Lanzkron explained the hub and spoke process in more detail. Derek Robertson explained the Pathway Grant which is from the Maryland Community Health Resource Commission, established under the Shirley Nathan-Pulliam Health Equity Act of 2021. It is an initial 2-year award to recipients, who would then be able to prepare to apply for a 5-year award that is called a Health Equity Resource Commission award. Derek informed the committee that he had the honor of presenting this year at the 50th anniversary event for the Legislative Black Caucus of Maryland. The legislators of Prince George’s county were very interested in making sure Prince George’s County residents receive services.

B. Sickle Cell Trait
Rudy Williams reported that the team had a meeting on October 26th. It was decided to pursue the availability of Sickle Cell Trait (SCT) testing as part of health fairs. Guidance from a few state delegates was received. The Maryland Department of Health (MDH) provided clarification as far as the guidance, as to SCD being a rare disease, and being able to test for sickle cell trait SCT and SCD at non-laboratory venues. A request went to MDH if they could give guidance on how to utilize testing outside of the lab for SCD and SCT at health fairs in 2022. Currently in Maryland the only outside-of-laboratory testing is taking place with the Red Cross. Donated blood is tested for SCT and information is passed along to the donor. It is not known whether this program will continue. An upcoming meeting has been scheduled to discuss guidelines. Clarification will help determine if the Sickle Cell Association of Harford and Cecil Counties and the Eastern Shore will pursue testing at health fairs administratively or legislatively.

C. Transition from pediatric to adult care
No updates.

Rudy Williams mentioned that he is attempting to fulfill the Transcranial Doppler Screening projects Dr. Bashai, the previous Harford County Health Officer, earmarked for the county. He will keep the committee updated.

Sophie Lanzkron met with CRISP and they are going to set up a dashboard in CRISP for SCD. Providers have to sign up for it. CRISP needs a statement of purpose and why SCD belongs on the dashboard. The dashboard will give a lot of identifying information such as what hospitals people are going to, how many people are being hospitalized, and in what regions. The committee can think strategically about where more resources should be placed once the information is received. Dr. Lanzkron will get that one pager completed and sent to CRISP.

Derek Robertson inquired about ending terms. Monika gave the existing term cycles. She turns in yearly attendance records. That will determine if members will need to fill out exemptions or be removed from the committee. A list will then be generated of who is on the committee, what seats are filled, and who is up for renewal. Monika informed the committee that relevant information is on the master list that everyone should have access to.
Derek Robertson asked, for the record, if any clinicians have any COVID-19 updates or guidance. Sophie Lanzkron said everyone should get a vaccine booster. Andrew Campbell mentioned he has noticed some hesitation in the 5-11 year old age group. Overall, the vaccines in the younger kids are going well. More outside vaccinations being done as opposed to in the clinics. An increase in vaccinations is expected in January-February.

Rudy Williams mentioned that the University of Maryland announced yesterday that Elizabeth Wise from the Health Care Network of Lehigh Valley Hospital will be replacing Lyle Sheldon effective January 10, 2022. Mr. Sheldon will be stepping down from service from Upper Chesapeake, University of Maryland and Harbor Memorial Hospitals.

The next meeting has been scheduled for March 9, 2022 at 10am- 12pm. Invites will be sent out.

Meeting was adjourned at 4:20 pm.