Statewide Steering Committee on Services for Adults with Sickle Cell Disease

Meeting Summary

Date: September 23, 2021
Time: 10 am-12 pm

Location: Online

Committee Members Present: Lanzkron, Sophie; Williams, Rudolph; Baker, Francine; Brown Gay, Virginia; Law, Jennie; Callahan, Chuck; Derek Robertson; Nnake, Ijeoma;

Committee Members Absent: Fitzgerald, Shantia; Fixler, Jason; Francis-Gibson, Beverley; Martin, Abbie; Pecker, Lydia; Riley, Crystal; Strawberry, Dyshekia; Taylor, James; Campbell, Andrew; Williams, Paul; Butler, Camile

Committee Co-Chairs: Sophie Lanzkron and Derek Robertson

Committee Staff Present: Monika Piccardi

Guest Present: Jed Miller, Brian Taylor, Tana Sarntinoranont, David Bashai, Sara Roberson, Anjuna Rao and Adrian Gray

The Steering Committee meeting was called to order at pm. by Derek Robertson.

The Committee reviewed the last meeting minutes from the May 12, 2021 meeting. The minutes were discussed but not approved because there was no quorum for official business.

Workgroup updates

A. Access to care in PG County

Derek Robertson informed the committee that Capital Region Health Hospital has opened and is seeing patients. There has been some press reports of people not being too happy of the wait times but that may just be related to normal troubles at every hospital now during these times. He stated the committee will be meeting with them. Derek mentioned another group that was formed prior to this committee which is a group of PG Co. advocates, himself, Dr. Lanzkron, Rudy, Dr. Campbell and Francine and they are meeting with Capital Region Health some time today to get an update on where things are with SC. A SCD patient that was in a crisis and choose to go to the Institution to see what it was like and will be giving a firsthand look of her experience of going. Positive steps are being made. They have hired a Doctor who is a provider with an interest in SC. He is a pain management specialist by the name of Dr. Zima. Derek committed to bringing this group together to get filled in on with contributing to whatever efforts. Dr. Lanzkron sees positive making efforts. She said they were included in an implementation grant and providing resources and they are reaching
out. This will take some time to get it all up and running but its positive.

B. Sickle Cell Trait
Rudy Williams reported the team has not met since the last meeting, however the good news is as of April, The Red Cross’s blood drives have been testing each donor for SC trait. He will need to get clarity of the process of notifying the individuals once they give their blood and how it trickles down to the donor. Should have more information on next meeting. Rudy promised that the committee will meet before the next meeting to get together and brain storm a strategy for SC trait. Derek agreed with Rudy that each member must commit to get something done in between the next meeting. He said there is a lot of things going on in the SC trait and a lot of things to be done in trait. A Congressional SC Caucus briefing was held and Congresswoman Lee raised SC trait as an issue as to why there is not more education around it so that there may be opportunities for funding from the Federal side if there is ever any funding coming that would include SC trait awareness. Monika and Jed gave a brief update on SC trait within the State level.

C. Transition from pediatric to adult care
No updates. Francine was asked to put a meeting together with issues, questions and doable goals.

Dr. Bashai, Health Officer of Harford County had a discussion on Transcranial Doppler Screening Technology. He explained it is an evidence based screening that is available to pediatric population that should be done annually. It can detect low flow states in carotid arteries in children. If an obstruction is noticed, a clinician can intensify treatment for SC disease and lower risk of stroke. Past literature on this technology has shown in some places that have been studied the compliance is not 100% and studies that have been published have found it being missed as a routine part of care a fair amount of time. Dr. Bashai is unable to find out the rate of patients in Harford County, what their compliance rate is. He reached out to CRISP to ask them as an health officer, could he request a data pull for patients that have a ICD code for SC that have received care with the Harford County zip code in order to form a registry and as a practice matter as the health office reach out to the families and assess their compliance with Doppler Screening. An option that CRIPS could potentially do is a direct interrogation of compliance with Doppler Screening. Dr. Bashai will be discussing with CRIPS in the next few days

The committee discussed CRISP and adding SCD to CRISP dashboard.
Dr. Lanzkron just had a meeting with CRISP. Identifiable data was a crucial question. They have three different ways of getting data, one is the dashboard. Dr. Lanzkron has access to their data dashboard now. SC disease is not on the dashboard. She shared the CRISP public health dashboard with the committee. It was suggested a letter be submitted by the committee requesting to have SC added to the dashboard. No Legislation needs to be done Dr. Lanzkron will have the letter sent around to the committee for voting.
Dr. Lanzkron asked the committee their comfort level in having the Department of Health know the names and addresses of children with SC disease. Surveillance and screening identify people who need care and if you don’t have a name, you can’t find people. Chuck Callahan mentioned there is a form to opt out of CRISP and anyone can do it which is one disclaimer that can be put out there. He said that more of this kind of data from people willing to share, the better to care for the population. Dr. Jed Miller mentioned points of vulnerability for patients.
Derek Robertson said privacy is a touchy issue and transparency would need to be discussed with the community to make people aware of what exactly is going on. The committee discussed should there be legislation that allows CRISP identifiable data to be transmitted to the Maryland Department of Health. Dr. Lanzkron will have something sent out to the committee to vote if they are comfortable with that legislation. Dr. Jed Miller touched on MDH pursuing business associate agreements with Medicaid so that identifiable data is transmitted to MDH.

Committee members meeting nonattendance and the committee guidelines that states that attendance is required was discussed. Finding new committee members was a suggestion. It was decided to contact committee members in regards to their attendance and if they would still like to be a part of the committee.

Dr. Miller made mention of the Open Meetings Act in regards to a letter Dr. Lanzkron mentioned earlier to email to the committee for a vote. He said the Open Meetings Act states no vote can be conducted through email but he informed the committee that he will look into it further and report back to them regarding the matter.

The next meeting has been scheduled for December 8, 2021 from 3pm-5pm. Invite will be sent out.

Meeting was adjourned at pm.