

Statewide Steering Committee on Services for Adults with Sickle Cell Disease

Meeting Summary

Date: May 12, 2021

Time: 3:15 pm-5:15pm

Location: Online

Committee Members Present: Lanzkron, Sophie; Francis-Gibson, Beverley; Taylor, James; Strawberry, Dyshekia; Williams, Rudolph; Robertson, Derek; Butler, Camile; Baker, Francine; Callahan, Charles; Campbell, Andrew

Committee Members Absent: Brown Gray, Virginia; Fitzgerald, Shantia; Fixler, Jason; Law, Jennie; Martin, Abbie; Nnake, Ijeoma; Pecker, Lydia; Riley, Crystal; Williams, Paul

Committee Co-Chairs: Sophie Lanzkron and Derek Robertson

Committee Staff Present: Monika Piccardi

Guest Present: Jed Miller, Maryland Department of Health

The Steering Committee meeting was called to order at 3:16 pm. by Derek Robertson.

The Committee reviewed the last meeting minutes from the February 10, 2021 meeting. The minutes were discussed but not approved because there was no quorum for official business.

New committee member Paul Williams was introduced in his absence. Paul is a college student living with sickle cell disease (SCD). He and his mother are active with the Maryland Sickle Cell Disease Association. Derek had reached out to Paul to apply because there are no current members on the committee living with SCD.

Derek noted that it was discussed to have different group leads and plans for access to care. He didn't think that worked out so he and Sophie talked about how the group could produce something from the meetings. They recognized the challenges with everyone being busy but they wanted to get feedback from the committee on the idea of focusing on one area. This committee is a small enough group to decide what to be done in this area. It was discussed coming up with some recommendations to present to the State. Those recommendations could be a springboard for other things, and other groups could take to legislation or something else. Sophie added that they wanted to have something and be focused on the committee's goals. She said of course to bring up issues as they come but they also want to reinforce a set goal for the committee that would be doable. Potentially having these recommendations eventually made public on different platforms as tools would be helpful for all while recognizing the committee. Sophie suggested that over the next couple of meetings these goals and/or recommendations could be identified, and the committee could pick one. Derek added to use the meetings as working sessions to brainstorm and come up with recommendations. He asked

the committee their thoughts and input. Those in attendance were in favor of this approach.

Sophie noted access to care being a broad point and would be a good place to start and brainstorm potential recommendations around issues of access to care. Derek noted that data would be needed as well to back up what the committee is doing. Derek proposed to begin this meeting with some recommendations. He began with the recommendation that the University of MD Capital Region of Health include adult SCD care in their new facility. Sophie recommended establishing a comprehensive SCD program for the adult population. Andrew recommended a Surveillance program as well as provider networks. Sophie suggested every person with SCD have access to an SCD specialist and access to telemedicine. James recommended removing Medicaid barriers for care. Francine recommended a community health worker force to enable patients who are transitioning to establish care. Members in attendance shared more recommendations, and Derek asked Monika for the list she had captured so that it could be finalized and sent back to the committee to prioritize each recommendation. Sophie stated to the committee to feel free to add any recommendations they may think of later.

Sophie stated that a lot of her patients have been vaccinated and in general they have tolerated it very well. A few had crises like pain afterwards but nothing dramatic. SC patients have been able to tolerate the COVID vaccine. Andrew added the Prince Georges County Center has a weekly vaccine clinic that has vaccinated hundreds of SCD patients successfully. Vaccinations for kids are about to begin. Monika noted that the Maryland vaccination site is up now allowing for 12 year olds to register.

Andrew shared data charts from Children's National Hospital on transitioning adults with SCD with the committee.

Monika informed the committee MDH is currently working on shareable sickle cell data for the public. Jed added that MDH will hopefully have some updates available in the upcoming months.

Jed suggested having a discussion with CRISP, due to CRISP coming up during this meeting and last year's presentation by Dr. Marc Rabner from CRISP. Dr. Rabner has asked about the committee and would be willing to join another meeting. CRISP has a lot of data and would be happy to share.

Jed noted the availability of COVID data on the MDH website and the committee to take a look at the data.

Derek asked Monika to send out a reminder to committee members to attend the meetings.

The next meeting date/time will be September 15, 2021 from 10 am to 12 pm.

Beverley gave the committee a few updates for World Sickle Cell Day. She also noted the Therapeutics Conference coming up September 15th and other upcoming events.

The meeting was adjourned at 4:53 pm.