

Statewide Steering Committee on Services for Adults with Sickle Cell Disease

Meeting Summary

Date: November 18, 2020

Time: 10 am-12 pm

Location: Online

Committee Members Present: Baker, Francine; Butler, Camile; Callahan, Charles; Fixler, Jason; Francis-Gibson, Beverley; Lanzkron, Sophie; Martin, Abbie; Nnake, Ijeoma; Taylor, James; Williams, Rudolph; Robertson, Derek

Committee Members Absent: Brown-Gray, Virginia; Fitzgerald, Shantia; Law, Jennie; Pecker, Lydia; Riley, Christal; Strawberry, Dyshekia

Committee Co-Chairs: Sophie Lanzkron and Derek Robertson

Committee Staff Present: Monika Piccardi

Guests Present: Dr. Jed Miller

The Steering Committee meeting was called to order at 10:07 am. by Dr. Lanzkron.

The Committee reviewed the last meeting minutes from 08/09/2020. No changes were made and the minutes were approved as written by unanimous vote.

Reappointment of members was discussed. Those members that were reappointed were reviewed and open positions were discussed. Committee members will reach out to interested people, and the Sickle Cell Disease Follow Up Program will post the open positions to the Committee website. The Governor's appointments office will also advertise through their normal avenues. It was suggested that Dr. A. Campbell is offered another opportunity to become a member of the committee.

Derek Robertson reviewed and discussed the Committee's authorizing statute (Health General), workgroup updates and plans. The existing five workgroups were consolidated into three groups. Discussions as to the work of the groups took place.

A. Access to SCD specialists with two subgroups

- a. Prince George's County
- b. Eastern Shore

B. Sickle Cell Trait

C. Transition from pediatric to adult care

Each member was asked into which group they would be in and each group was asked to pick a “lead” for a series of one or two meetings. Each workgroup with directed to meet at least once in between full Committee meetings. See the workgroup list for details.

There was a brief discussion about determining a focus for the sickle cell trait (SCT) workgroup. Derek Robertson asked whether the Department was interested in an SCT follow-up program. Jed Miller said the Department does not have a specific interest but is receptive to learn about SCT to inform any planning considerations, and that the work of the SCT workgroup will be helpful in that regard. The possibility of a pilot SCT follow up assessment was initiated by Dr. Lanzkron, who asked how far back electronic newborn screening data exist and if data from 2010 or thereabouts could be retrieved, including names and addresses, to see what percentage of those identified with SCT are still residing in states and what SCT educational materials could be available for providers, families, and children. Monika will follow up to gauge the availability of newborn screening data for that purpose.

Monika Piccardi gave an update on the SCD Long Term Follow Up Program. The parent mentor program is in need of parents (moms and dads). The committee members were asked to identify potential volunteers and contact Monika. Ms. Francis Gibson offered to place a notice on the SCDA email blast.

The next meeting date/time will be February 10, 2021, from 3-5 pm

Open/public comments were given by Dr. Miller regarding the SCT follow up possibilities within the state’s SCD Long-term Follow up Program.

The meeting was adjourned at 1135 am