Statewide Steering Committee on Services for Adults with Sickle Cell Disease

Meeting Agenda
Date: February 10, 2021
Time: 3:15pm-5:15 pm
Location: Online

Committee Members: Baker, Francine; Brown Gray, Virginia; Callahan, Francis-Gibson, Beverley; Lanzkron, Sophie; Pecker, Lydia; Taylor, James; Williams, Rudolph; Campbell, Andrew; Robertson, Derek
Committee Co-Chairs: Sophie Lanzkron and Derek Robertson
Committee Staff: Monika Piccardi
Guest Present: Dr. Jed Miller

The Steering Committee was called to order by Dr. Lanzkron at 3:18 pm.

The Committee reviewed the meeting minutes from November 18, 2020. No changes were made and the minutes were unanimously approved.

Reappointment of members was reviewed and discussed. Dr. Andrew Campbell was welcomed to the Committee. One position remains open and Committee members were given the website for interested parties to apply. The Governor’s appointments office continues to advertise through their normal avenues. There was some discussion as to whether to keep the number of members “as is” or advocate for more members, though no firm resolution was made.

Workgroup updates and plans were provided from group leads. It was advised that each workgroup should meet at least once prior to the next Committee meeting. Mr. Robertson discussed the possibility of the Committee presenting an (annual) report to the Secretary. Information from Medical Assistance was suggested to be included and Dr. Miller advised that the Medical Assistance Administration is separate for the Prevention and Health Promotion Administration, which is staffing the Committee. Should the Committee want to explore work with Medical Assistance, an appropriate person may be identified. Workgroup membership was discussed in each of the following groups:

A. Access to care (Prince George’s County/Eastern Shore)
B. Sickle Cell Trait (SCT)
C. Transition from pediatric to adult care

The Committee assigned Dr. Campbell to the Transition workgroup and Dr. Fixler will be asked to lead this workgroup. During the Sickle Cell Trait workgroup discussion, Dr. Miller gave an update on what data may be available from the State public health laboratory with regards to SCT and the newborn screening process. Data are available from 2009 through the present, and Department interest and planning would be needed before further consideration. The Committee discussed SCT testing and education issues with both providers and the community.
Key issues are the age at which knowledge of SCT status is most valuable and what exact knowledge would be conveyed to individuals with SCT, and the potential role of providers in communicating that knowledge. Ms. Piccardi discussed the Department survey that was done with regard to community provider awareness of Sickle Cell Trait testing on the newborn screen as well as general awareness of the complications of trait.

Mr. Williams discussed the work of having a blood drive on the Eastern Shore and awareness of an infusion center on the Eastern Shore as well. Dr. Campbell mentioned that his patients are working with Tidal Health on the Shore, and he and Dr. Lanzkron will work together on ascertaining the possibility of training and telehealth for Shore residents. Dr. Taylor will work with the transition workgroup.

COVID vaccinations were discussed in general, and the question arose about studies specific to the sickle cell community. It is thought that the American Society of Hematology may be conducting some studies related to this. The Sickle Cell Disease Association of America will be hosting a virtual event by Dr. Hsu discussing the COVID vaccine.

Under New Business, a 1-800 line for Sickle Cell Disease was discussed. Several hospitals have such disease specific numbers staffed by providers. The possibility of the Department hosting such a line was a discussion point. Dr. Miller said there were examples of toll-free lines for “warm” consultations, and that such services would require funding and have structural considerations, such as what agency or organization implements the service. Medical liability was identified as a key consideration for a toll-free service, and one option might be to have calls routed to a provider’s home institution and therefore covered by their existing liability policy. Mr. Robertson brought up the concern that community providers might not be following standards of care, which may support the creation of such a line. JCAHO standards could support needs as well; not many hospitals are accredited by JCAHO of sickle care. This topic remains open for discussion.

Next meeting will be held on May 12, 2021 from 3 pm-5 pm.

There was one public comment from Dr. Miller in which he asked whether anybody on the group has had or knows of experience with monoclonal antibody treatment for COVID in individuals with Sickle Cell Disease. Dr. Lanzkron stated the antibody treatment was not contraindicated and other therapeutic options should be coordinated with their doctor (specialist). Dr. Miller notes that the currently-licensed vaccines for those ages 16 and 18 or older, and that use in younger people is still being studied.

The meeting was adjourned at 4:50 pm.