

Sickle Cell Subcommittee

Meeting Minutes

July 7, 2023

1:00 p.m.

Location: Microsoft Teams

Table 1. Subcommittee member attendance at the Friday, July 7, 2023 meeting.

| MEMBER NAME | IN ATTENDANCE |
|---|---------------|
| Titilope Fasipe, M.D., Ph.D. (Subcommittee Co-Chair) | Yes |
| Melissa Frei-Jones, M.D. (Subcommittee Co-Chair) | Yes |
| Elizabeth (Kaili) Stehel, M.D. | No |
| Alice Gong, M.D. | Yes |
| Michael Speer, M.D. (Ex-officio) | Yes |

Table 2. Texas Department of State Health Services (DSHS) Newborn Screening (NBS) Unit staff attendance at the Friday, July 7, 2023 meeting.

| ATTENDEE NAME | IN ATTENDANCE |
|--|---------------|
| Laura Arellano, Unit Coordinator, DSHS NBS Unit | Yes |
| Karen Hess, Unit Director, DSHS NBS Unit | No |
| Aimee Millangue, Advisory Committee Liaison, DSHS NBS Unit | Yes |
| Juliana Ybarbo, R.N., Nurse Lead, Cystic Fibrosis (CF), Hemoglobin and Severe Combined Immunodeficiency (SCID), DSHS NBS Unit | Yes |
| Selda Rios, Manager, CF, Hemoglobin and SCID, DSHS NBS Unit | Yes |

Previous Subcommittee Business

The subcommittee last met by Microsoft Teams on January 3, 2023 and reported to the full committee at the March 24, 2023 Newborn Screening Advisory Committee (NBSAC) meeting.

Prior to the subcommittee meeting, Aimee Millangue, DSHS, NBS Unit, Advisory Committee Coordinator and Ombudsman, emailed attendees the January 3, 2023 subcommittee meeting minutes.

Subcommittee Meeting Notes

Dr. Titilope Fasipe, Co-Chair of the Sickie Cell Subcommittee, convened the meeting at 1:04 p.m. Attendees exchanged greetings and provided introductions. Ms. Millangue recorded and transcribed the meeting through Microsoft Teams.

Action item review

- Role of the Sickie Cell Task Force versus the Sickie Cell Subcommittee
- Letters of support for the Centers for Disease Control and Prevention (CDC) surveillance grant application and provider survey
- Program staff resending the provider survey to get additional responses

Member discussion:

Legislative update

- Status of Sickie Cell Task Force-related bills during the legislative session and whether they received funding.
- Sickie Cell Task Force bill did not have a fiscal note and included expanding expertise and education components.
- Sickie Cell Registry bill passed; Governor vetoed the bill based on security.

Sickie Cell Surveillance

- Outside of the Sickie Cell Registry bill not going through, DSHS submitted grant application for sickie cell surveillance
- Regardless of the outcome of the registry bill, the grant application is good news
- They expect to hear about whether they get the grant in August
- Due to a series of events that included meetings with the Community Health Improvement Division Medical Director, Dr. Kelly Fegan-Bohm, and a DSHS Epidemiology group, a NBSAC letter of support was not needed for the grant application.

- That DSHS would be the home of the grant is the best outcome Dr. Fasipe and Dr. Frei-Jones hoped for from their work on the Sickle Cell Surveillance Subcommittee of the Sickle Cell Task Force, Sickle Cell Advisory Committee, and the Sickle Cell Task Force.
- A centralized group was needed for managing sickle cell data collection instead of an individual university or institution.

Adult provider survey

- Clarifying what the process is of getting a letter of support for sending out the provider survey from the NBSAC to the Texas Pediatric Society (TPS), since it has already been written and was reviewed by Dr. Gong and Dr. Speer.

National Collegiate Athletic Association (NCAA) sickle cell status policy

- If the Newborn Screening Program email notices about athletes having to disclose their sickle cell status was a legislative mandate.
- Whether the National Collegiate Athletic Association (NCAA) sickle cell status policy has caused an uptick in teen sickle cell trait patients making appointments at hematology clinics.
- The American Academy of Pediatrics and the American Society of Pediatric Hematology/Oncology are working on a joint guideline and a document to help with the sickle cell trait conversation on how to give appropriate trait counseling at different life stages, which is a long-standing issue.
- It is hard to give balanced education with the NCAA report that came out, since it will be incorporated.
- If DSHS could handle the number of trait status requests from athletes, and if it is only from students on a college level.
- NCAA policy implementation varies among institutions and is causing pushback.
- Student athletes either request their newborn screening results or just pay \$50 to get the test done.
- The NCAA required sickle cell solubility test is not the recommended test by the American Society of Hematology.

- The issue of providing sickle cell trait status stigmatizing or negatively impacting players and what the alternatives could be.

Long-term follow up form

- Limitations on the long term follow up form as they stand right now
- Forms are fax hard copy documents faxed between the DSHS Newborn Screening Unit (NBS) to the various clinics that accept newborns with sickle cell disease, the hematology clinics, and NBS is reliant on those clinics to send back the information.
- No electronic system exists, but the NBS Program has been evaluating options.
- Improving long-term follow up data collection.
- Whether the long-term follow up form needs to be changed with new drugs and sickle cell care updates.
- Who updates the form and how often.
- If the Sickle Cell Subcommittee could perform an annual review.
- No one has received reports about the data collected, so what is being done with it?
- Needing to push issue of getting data reports because if DSHS is asking centers to collect and send data, there are the questions of where the data is going and how many years of data there are.
- Comparing what is done for sickle cell long-term follow up data to what is done for Critical Congenital Heart Disease reporting.
- If reports are not generated, the data does not get usage, and that does not drive better care.

ACTION ITEMS

- Program staff will reach out to get additional guidance on whether the NSBAC could send a letter requesting support from TPS.
- Future agenda item of a long-term follow-up data report to include how many forms NBS has gotten back, how many sickle cell positive results are there every year, and quality measures such as the number of babies receiving penicillin.
- Follow up on Action (ACT) and Fact sheet updates.

Ideas/Next Steps

- Follow up with the DSHS Newborn Screening Laboratory to see how the NCAA policy is causing increased numbers or difficulty.
- Provide long-term follow-up data feedback to the NBSAC.

Dr. Fasipe adjourned the meeting at 1:52 p.m.