

**Sickle Cell Task Force
FINAL APPROVED Meeting Minutes
June 10, 2021
1:00 p.m.**

Microsoft Teams Live Event

Table 1: Sickle Cell Task Force member attendance at the Thursday, June 10, 2021 meeting.

MEMBER NAME	IN ATTENDANCE
Dr. Titilope Fasipe	Yes
Dr. Melissa Frei-Jones	Yes
Dr. Michelle Mackey	Yes
Dr. Alecia Nero	Yes
Ms. Marqué Reed-Shackelford	Yes
Ms. Alysian Thomas, J.D.	No
Vacant	Not applicable

Agenda Item 1: Welcome and Introductions

Dr. Michelle Mackey, Chair of the Sickle Cell Task Force (SCTF), called the meeting to order at 1:01 p.m. and welcomed everyone in attendance. Dr. Mackey provided opening remarks and asked the agency staff to introduce themselves.

Agenda Item 2: Task Force Logistical Announcements, Roll Call

Dr. Mackey introduced and turned the floor over to Mr. Eric Owens, HHSC, Policy & Rules, Advisory Committee Coordination Office (ACCO). Mr. Owens reviewed logistical announcements, conducted a roll call, asked members to introduce themselves, and announced the presence of a quorum.

Dr. Mackey announced that member Tonya Prince has resigned from the Task Force.

Agenda Item 3: Review and Approval of Meeting Minutes from April 8, 2021

Dr. Mackey requested a motion to approve the April 8, 2021 meeting minutes.

MOTION: Dr. Frei Jones motioned to approve the April 8, 2021 meeting minutes. Ms. Marqué Reed-Shackelford seconded the motion. Mr. Owens conducted a roll call vote, and the motion carried with no objections and no abstentions.

Agenda Item 4: Collaborating with Community Health Workers

Dr. Mackey introduced and turned the floor over to Mr. Brett Spencer, DSHS, Manager, Community Health and Wellness Branch. Mr. Spencer introduced and shared the floor with Mr. Frank Luera, DSHS, Program Coordinator for the Community Health Worker (CHW) Training and Certification Program.

Mr. Spencer stated:

- Community Health Worker (CHW) Training and Certification Program administers the processes to certify CHWs, CHW instructors, training programs for CHWs, and Continuing Education Units (CEUs) for CHWs. 30 hours of CEU credits are required every two years.
 - Development is process oriented
 - Staff and program know about CHWs and the Core Competencies that they use in their everyday work
 - Service coordination
 - Education on health topics
 - Outreach
 - Continuity of care
 - General support to improve health outcomes
 - CHWs are employed by local health departments and other health care organizations. CHWs are certified but are not considered medical experts on any given health topic, but CHWs can promote topics.
 - Opportunities for collaboration on specific conditions or health topics:
 - Connections to CHWs and training centers
 - Through the Promotor(a)/ CHW Training and Certification Advisory Committee, which includes representatives from training programs and CHW associations
- Ways to raise awareness of sickle cell among CHWs
 - Sharing communications through the CHW Program's email distribution list
 - Through training and certification processes
 - Helping to distribute printed resources and awareness materials
- Funding opportunities for CHWs
 - Medicaid
 - Through advisory committee, continually pushing to improve how funding is allocated and allowed
 - Payment for CHW services through Fee-for-service is the goal but a challenge to get to
 - Managed Care Organizations usually charge CHW services under administrative services or quality improvement services, not as a service in and of itself
 - DSHS partners with programs and groups and can encourage having CHWs included in grant opportunities
 - Looking at the science and literature on the cost-effectiveness of

CHWs and increasing their opportunities by working directly with organizations to engage them on various health topics across the state

Members discussed:

- What would go into the process of creating a certified CEU module to educate CHWs on sickle cell disease
- Promoting module to primary care-based CHWs
- Texas Health Steps Sickle Cell module is certified for CHWs and any additional module would be complementary to that module
- Possibility of providing education and promoting full training through the modules at an annual meeting of CHWs
- Texas CHWs aren't employed by a single large organization, so there's no central decision maker on what the priorities are or what topics to focus on

ACTION ITEM: Mr. Luera will coordinate putting sickle cell on the agenda and inviting Task Force members to present at a future Promotor(a)/ CHW Training and Certification Advisory Committee meeting.

Agenda Item 5: Michigan Public Awareness

Dr. Mackey introduced and turned the floor over to Dr. Wanda Whitten-Shurney, Chief Executive Officer (CEO) and Medical Director of the Sickle Cell Disease Association of America (SCDAA) – Michigan Chapter (MI), Ms. Mary Robinson, B.S.N., Special Projects Coordinator, Public Health Genomics Section, Division of Lifecourse Epidemiology & Genomics, Michigan Department of Health & Human Services (MDHHS) and Ms. Dominic Smith, M.S.A., Manager, Public Health Genomics Section, Division of Lifecourse Epidemiology & Genomics, MDHHS.

Dr. Whitten-Shurney referenced the handout and presentation, *Raising Sickle Cell Awareness*.

Dr. Whitten-Shurney stated:

- Major awareness-raising events and activities include:
 - Annual walks in September as tribute to fallen sickle cell warriors Myth dispelling walks
 - Campaigns for World Sickle Cell Day on June 19
 - "Shine the Light on Sickle Cell Disease" annual campaign
 - Lantern release
 - Statewide campaign with a different theme each year such as "High 5 for Sickle Cell," "Mask up for Sickle Cell," "Know Your Status" and "Know the Facts"
 - National SCDAA campaign raises funds by selling a t-shirt for people to wear on June 19; t-shirt is designed by an artist living with SCD and reflects a different theme each year
 - Bill passed in Michigan for a SCD awareness license plate

- Advocacy Days to meet with state representatives and staff
- There is a need for primary care providers for adults living with SCD
 - How primary care differs from specialized care from hematologists
 - Lunch and Learns help to educate providers on patient needs
- Patient empowerment toolkits have been developed
 - Backpack has items that help patients hospitalized with SCD
 - Includes patient's medical history and guidelines to share with doctors
- Some other ways of sharing sickle cell information and promoting awareness
 - *Cheat Codes*, a sickle cell podcast hosted by two doctors
 - You Tube videos
 - Animated whiteboard, *Questions about Hydroxyurea*
 - Tutorial for "Sickle Slide," a dance move performed at annual walks

Ms. Robinson and Ms. Smith referenced the handout and presentation, *Overview of Michigan's Hemoglobinopathy Quality Improvement Initiatives*.

Ms. Robinson and Ms. Smith stated:

- MDHHS and SCDA-MI have had a partnership since 1987
- MDHHS Hemoglobinopathy Quality Improvement (QI) Program works to implement a comprehensive public health plan to address the needs of children and adults with hemoglobinopathies, particularly SCD, across the lifespan
- Work with Immunizations, as not all SCD patients are up to date with immunizations.
- Work with health plans
 - Hemoglobinopathy Quality Improvement Committee (HQIC) is one of 8 condition-specific MDHHS committees with the main purpose to provide expertise and guidance for newborn screening
 - 3-year Public Health Strategic Plan for 2015-2018 to address SCD across the lifespan
 - Developed in 2014 by conducting focus groups
 - Identified a number of state health priorities and listed projects and activities
 - Received special designation from the Health Resources and Services Administration (HRSA) and has served as a model for other states
 - Not everything was accomplished within 3 years, so work is continuing and evolving
 - Work is especially needed to address SCD health disparities
 - Children's Special Health Care Services (CSHCS) Division includes benefit programs that help SCD patients
 - Children's Multidisciplinary Specialty Clinic Program
 - Children's Special Health Care Transition Assistance Program
 - A document, *Quick Look at Vaccines Needed for Persons with SCD* was created by MDHHS Department of Immunizations to provide

- guidance to primary care physicians and hematology clinics on vaccines needed by SCD patients and is embedded in the Michigan immunization registry to notify providers automatically
 - Created a sickle cell pain management course, *Pain Management Education Webinar for Healthcare Professionals*
 - HQIC members participate in meetings to decide Michigan Medicaid Managed Health Plan Common Formulary Prior Authorization Criteria to improve access to medications
- Michigan has been part of the HRSA Sickle Cell Treatment & Outcomes Research in the Midwest (STORM) Cooperative Agreement since 2015
 - Includes STORM TeleECHO, a monthly webinar, which is open for participation from providers in other states
- Michigan Governor's Office has recently formed a Sickle Cell Task Force
- Governor signs annual Proclamation of World Sickle Cell Day on June 19
- Awarded grants Centers for Disease Control & Prevention (CDC) Sickle Cell Data Collection (SCDC) Program since 2019
 - Data piece is led by University of Michigan Child Health Evaluation Research Center, which received public health authority to develop a sickle cell disease surveillance framework and platform
 - A multi-disciplinary team component is led by MDHHS
- "MDHHS Proposal for Change Initiative" for CSHCS Adult Benefit Expansion is under review by the Michigan state legislature
- Resources are available on the Michigan Hemoglobinopathy QI Program webpage

Members discussed:

- Audience for Advocacy Days
- Relationship between Dr. Whitten-Shurney, as a physician and CEO and Medical Director of the SCDA-MI, and the MDHHS Hemoglobinopathy QI Program
- How Michigan differs from Texas in addressing SCD
- Taking inspiration from Michigan in making SCD a priority and how they grew their efforts to help identify next steps for Texas
- Appreciation for Dr. Whitten-Shurney, Ms. Smith, and Ms. Robinson for their time and for sharing what is being done in Michigan

Agenda Item 6: Public Awareness Campaigns Subcommittee Reporting

Dr. Mackey introduced and turned the floor over to Ms. Marqué Reed-Shackelford, subcommittee member. Ms. Reed-Shackelford referenced the handout and presentation, *Public Awareness Campaigns Subcommittee Meeting Minutes, May 19, 2021*.

Ms. Reed-Shackelford stated:

- Subcommittee discussed:
 - The presentation that Ms. Smith and Ms. Robinson would be providing

- at the Task Force meeting
- Partnering with the University of Texas (UT)
- Collaboration opportunities

Members discussed:

- Thanking the subcommittee for inviting Michigan group to present
- How Johns Hopkins University might be a good resource on public awareness campaigns

ACTION ITEMS:

- Dr. Alecia Nero will reach out to Johns Hopkins University about presenting to the Task Force about what work and didn't work for them for their public awareness campaigns.
- Program staff will invite a representative from the University of Texas Human Dimensions of Organizations program to present at the next meeting

Agenda Item 7: Medicaid Contracts Subcommittee Reporting

Dr Mackey introduced and turned the floor over to Dr. Titilope Fasipe, subcommittee member. Dr. Fasipe referenced the handout and presentation, *Medicaid Contracts Subcommittee Meeting Minutes, May 19, 2021.*

Dr. Fasipe stated:

- Subcommittee has been happy with some of the connections they've made with Managed Care Organizations (MCOs)
- Decided the most important feature is to continue talking with the directors and making them aware of issues
 - Issue with patients becoming adults and losing Medicaid coverage
 - Sickle cell providers have not been compensated in serving this population is also an issue
 - Glad that there is an exclusion for access to opioids and pain medications for sickle cell patients, there is an ongoing issue that insurance companies, prescribers and pharmacies need to be educated that there is no opioid crisis within the sickle cell population as there is in the general population
 - Concerns that in an MCO attempt to coordinate care, but the medical home is left out. Deferring to only the primary provider may lead to confusion, duplication of services, and may end up harming the patient

Agenda Item 8: Sickle Cell Surveillance Subcommittee Reporting

Dr. Mackey introduced and turned the floor over to Dr. Melissa Frei-Jones, subcommittee member. Dr. Frei-Jones referenced the handout and presentation, *Sickle Cell Surveillance Subcommittee Meeting Minutes, May 18, 2021.*

Members discussed:

- If Chair appointment of another member to the subcommittee to replace former member, Tonya Prince will be decided at a later time, depending on membership availability
- Feedback on Texas Syndromic Surveillance (TxS2) report was provided
- Status of House Bill (HB) 3673 for creation of a state sickle cell registry
- If HB 3673 does not pass, developing a recommendation for the creation of a state sickle cell registry

ACTION ITEM: Program staff will contact Susan Paulukonis with Tracking California to invite her to present at a future subcommittee or Task Force meeting.

Agenda Item 9: Legislatively Mandated Subcommittee Reporting

Dr. Mackey referenced the handout and presentation, *Legislatively Mandated Report Subcommittee Meeting Minutes, May 18, 2021*.

Members discussed:

- Including in the appendices tables on hemoglobin diagnosed cases and sickle cell trait cases
- If there was any other information from Newborn Screening that could be included in the report

Agenda item 10: Legislative Update

Dr. Mackey introduced and turned the floor over to Ms. Taj Sheikh, DSHS, Government Relations Specialist, Government Affairs.

Ms. Sheikh stated:

- Brief wrap up of the 87th session:
 - 7148 bills filed, and of those, 1000 bills passed
 - As of June 7, 2021, 341 bills have been signed into law
 - Veto period ends June 20
- DSHS Statistics:
 - Monitored and assigned 672 bills
 - 71 bills assigned were passed as of June 7, 2021
 - 17 have been sent into law
- Budget Highlights - Exceptional Item/Rider Highlights
 - Addressed HIV program shortfall
 - Added full time employees for several programs
 - Children and Pregnant Women Case Management program will be transferred to managed care beginning in Fiscal Year 2023
 - Maternal Morbidity and Mortality will have continued funding from the 86th Legislative session
 - Additional \$1 million to continue the Alzheimer's awareness campaign
- Overall physical impact of bills:

- 12 bills have no significant physical impact
- 9 of those bills have a significant impact
- Total impact of approximately \$4.12 million
- HB 3673, filed by Representative Jarvis Johnson and relating to the establishment of a sickle cell disease registry, did not pass
- HB 133, relating to the provision of certain benefits under Medicaid and the Healthy Texas Women Program and included parts of Senate Bill 1149, was sent to the Governor as of June 1

Agenda Item 11: Review of Task Force Milestones

Dr. Mackey referenced the handouts, *April 8, 2021 Sickle Cell Task Force Draft Meeting Minutes, Task Force Milestone Development Subcommittee Meeting Minutes, June 26, 2020, and 2020 Sickle Cell Task Force Annual Legislative Report*. Dr. Mackey opened discussion to the Task Force for any updates to the milestones they had previously developed and listed in their 2020 report.

Members discussed:

- Modifying the milestone of tying COVID-19 into a public awareness campaign
 - It is a milestone the Task Force was not able to reach
 - Mention the importance of the COVID-19 vaccination within the sickle cell population into the milestone
 - Modification to vaccine hesitancy

Agenda Item 12: Development of Recommendations for the 2021 Sickle Cell Task Force Annual Report

Dr. Mackey opened the floor for discussion of the development of recommendations for the *2021 Sickle Cell Task Force Annual Report*.

Members discussed:

- Including care packages in Medicaid contracts
- Requirements for the legislative report
- Guidelines about stroke screenings
- Having the Texas Syndromic Surveillance Report be an annual report, and to include it in the legislatively mandated report
- Public awareness campaign for September 2021
- Developing a recommendation for a statewide sickle cell registry
 - Language can include "lifespan," "universal," and "database"
- Working on public awareness campaigns with college students and that college students were a good audience for outreach
- Working with the UT Human Dimensions of Organizations program to explore asks related to public awareness
 - Increase sickle cell awareness
 - Increase sickle cell awareness on college campuses or how to work

- with college students to develop campaigns
- Listing recommendations in the report by subcommittee or by general theme
 - Extend the duration of the Sickle Cell Task Force past its current 4-year term
 - Most of the work has been at the foundational level
 - With the various assessments done through the subcommittees, realized infrastructure is not in place and time is needed to develop those areas
 - Development of education modules for primary care providers and Emergency Departments that aligns with national efforts
 - Medicaid Contracts Subcommittee recommendations
 - The 2014 National Institutes of Health (NIH) Guidelines and 2019-2020 American Society of Hematology Guidelines should be appropriately recognized and implemented for sickle cell care in Texas
 - Requesting ongoing representation with Medicaid Medical Directors to advise on policy and have contact with disease or patient experts to bring understanding of the specifics of care that the sickle cell population needs
 - Sickle Cell Surveillance Subcommittee recommendation
 - That the state present an annual report using available data on the state of sickle cell in Texas, which can be a tool for the Medicaid Contracts Subcommittee and to raise awareness among the legislature, community-based organizations, and various other groups
 - Public Awareness Campaigns Subcommittee recommendation
 - Using as an example the National Comprehensive Cancer's *Network COVID-19 Vaccination Guide for People with Cancer* to develop a document for SCD vaccination
- Future activities for the report
 - Improve health care disparities and increasing access by maximizing telemedicine
 - Collaboration with CHWs

Agenda Item 13: Public Comment

No public comment was received for this meeting.

Agenda Item 14: Future Agenda Items/Next Meeting Date/Adjournment

Dr. Mackey opened the floor for discussion of future agenda items and stated the next meeting is scheduled for August 20, 2021. Ms. Aimee Millangue, DSHS, Advisory Committee Liaison, Newborn Screening Unit, provided the status on the solicitation process for the current vacant position and membership terms ending August 31, 2021. Ms. Millangue also announced there will be an election for a new

chair at the next meeting since Dr. Mackey's membership term is expiring.

Action Items discussed during meeting:

- Contact Johns Hopkins University
- Contact Tracking California
- Invite Mr. Linc Allen to present the Syndromic Surveillance System report
- Invite UT Human Dimensions of Organizations Program to present at the next meeting

Members discussed:

- Who will be eligible to be present the August meeting
- If all positions are expected to be filled by the November meeting

Mr. John Chacon, HHSC, Policy & Rules, Advisory Committee Coordination Office (ACCO), advised that, in reference to the Sickle Cell Task Force bylaws, members will continue to serve as a task force member until the position has been filled.

Dr. Mackey thanked everyone and adjourned the meeting at 5:05 p.m.

Below is the link to the archived video of the June 10, 2021 Sickle Cell Task Force (SCTF) meeting that will be available for viewing approximately two years from the date the meeting was posted on the website and based on the DSHS records retention schedule:

[Sickle Cell Task Force 06102021](#)