

**Sickle Cell Task Force Meeting**  
**APPROVED Minutes**

**July 11, 2023**

**1:00 p.m.**

**Hybrid Meeting:**

**Microsoft Teams Virtual Meeting**

Robert D. Moreton Building  
Public Hearing Room M-100  
1100 W. 49th St, Austin, Texas 78756

**Agenda Item 1: Welcome, introductions, and logistical announcements**

Dr. Titilope Fasipe, Chair of the Sickle Cell Task Force (SCTF), called the meeting to order at 1:01 p.m. and welcomed everyone in attendance.

Dr. Fasipe introduced Ms. Tessa Buck-Ragland, Texas Health and Human Services Commission (HHSC), Policy & Rules, Advisory Committee Coordination Office (ACCO). Ms. Buck-Ragland reviewed logistical announcements, conducted a roll call, and announced that with six members present, the SCTF did meet quorum.

**Table 1. Sickle Cell Task Force member attendance at the Tuesday, July 11, 2023 meeting.**

<b>Member Name</b>	<b>In Attendance</b>
<b>Dr. Titilope Fasipe</b>	Yes
<b>Dr. Melissa Frei-Jones</b>	Yes
<b>Mr. André Harris</b>	Yes
<b>Dr. Dawn Johnson</b>	Yes
<b>Dr. Alecia Nero</b>	No
<b>Ms. Marqué Reed-Shackelford</b>	Yes
<b>Ms. Linda Wade</b>	Yes

Yes: Indicates attended the meeting

No: Indicates did not attend the meeting

Dr. Fasipe recognized the Texas Department of Human Services (DSHS) staff who were in attendance; Lori Gabbert Charney, Maternal and Child Health Section Director, Laura Arellano, and Aimee Millangue, Newborn Screening (NBS) Unit.

Dr. Fasipe provided opening remarks and paused for a moment of silence to reflect on the important work that the members and staff do and for those that have been lost to sickle cell disease.

**Agenda Item 2: Consideration of August 19, 2022, December 1, 2022, and February 24, 2023 draft meeting minutes**

Dr. Fasipe reminded members that the August 19, 2022, December 1, 2022, and February 24, 2023 draft meeting minutes were sent to them via email. Ms. Buck-Ragland, ACCO stated that members were sent August 19, 2022 and the December 1, 2022, draft minutes, and that the February 24, 2023 draft meeting minutes will be tabled until the next meeting. Dr. Fasipe acknowledged the change and asked if there were any edits or changes. Hearing

none, she requested a motion to approve the August 19, 2022, and December 1, 2022, draft meeting minutes.

**MOTION:** Ms. Marqué Reed-Shackelford motioned to approve the August 19, 2022, and December 1, 2022, draft meeting minutes as presented. Ms. Linda Wade seconded the motion. Ms. Buck-Ragland conducted a roll call vote, and the motion carried unanimously with six for (Fasipe, Frei-Jones, Harris, Johnson, Reed-Shackelford, Wade), no objections or abstentions.

### **Agenda Item 3: Membership updates**

Dr. Fasipe announced new members, Ms. Linda Wade and Mr. André Harris, and discussed House Bill (HB) 1488 passage and impacts to the SCTF. Dr. Fasipe referenced the handout, *H.B. No. 1488*.

#### **Highlights of the discussion included:**

- Ms. Wade and Mr. Harris introduced themselves, giving more background about their work with sickle cell disease and any comments they wanted to make.
- Acknowledging Ms. Wade and Mr. Harris for participating in subcommittee meetings before their full orientation.
- Acknowledging that HB 1488 amends Texas Health and Safety Code, Section 52.003 to allow the SCTF to add six members effective September 1, 2023.
- Adding members will bring the SCTF membership total to 13, which will allow the SCTF to add more people to their subcommittees and keep up the great work the SCTF has been doing.

### **Agenda Item 4: Legislative update**

Dr. Fasipe introduced Ms. Alison Hern, DSHS Government Affairs, Government Relations Specialist to update members.

#### **Highlights of the update included:**

- The dates of 88th Regular Session, including end date and veto period.
- The dates and agenda topics of the two special sessions the Governor has called so far.
- During the 88th regular session, over 8,000 bills were filed; of those bills, fewer than 1,300 were sent to the governor, and those bills were vetoed or became law.
- The Governor vetoed House Bill (HB) 181 by Representative Jarvis Johnson on June 17, 2023, and his veto statement can be viewed on the Texas Legislature online website at [www.capital.texas.gov](http://www.capital.texas.gov).
- HB 181 would have required DSHS to create a sickle cell disease registry and include sickle cell disease registry information in an annual report.
- HB 1488 by Representative Rose impacts several agencies, including HHSC, DSHS, Texas Education Agency (TEA), and graduate medical education programs.
- HB 1488 adds six members to the SCTF, requires the SCTF to include in the annual report a recommendation for improving sickle cell disease education for providers, extends the SCTF Sunset date to August 31, 2025, and requires collaboration among HHSC, TEA, and graduate medical education programs to improve sickle cell disease education for providers.
- The Governor signed HB 1488 into law on June 9, and the bill takes effect September 1, 2023.
- The DSHS role in implementation includes currently developing a plan to coordinate with HHSC on appointing new members to the SCTF.

#### **Member discussion:**

Sickle Cell Task Force • July 11, 2023 • APPROVED Meeting Minutes\_08\_18\_2023

- Thanking Ms. Hern for the thorough report and the champions for their support of the SCTF and thinking globally about the sickle cell community.
- How the SCTF started through legislative action, and their gratitude to the various representatives and senators that gave bipartisan support.
- Additions to the SCTF will open another arm of their work in education, which they had not fully had the opportunity to do yet and have the support at high levels to be effective.
- The implication of HB 181 being vetoed since DSHS applied for the Sickle Cell Data Collection Program and whether aspects of the legislation would impact the ability of DSHS to carry out the grant.
- While they will find out if Texas is selected for grant later this summer, HB 181 being vetoed will impact the Sickle Cell Surveillance Subcommittee recommendations for the legislative report; the SCTF should continue to include as recommendations in the SCTF legislative report the creation of a report and legislation to allow surveillance to be performed.
- The agency will continue to have internal discussions regarding the Centers for Disease Control and Prevention (CDC) grant and keep the SCTF apprised of the grant status.
- Seeing the positive side of the Governor veto statement because the Governor appears to want to support sickle cell and seeing it as an opportunity for more education, knowing Texas has been successful with other registries.
- Not being fully discouraged by the veto because things expressed in the letter may not overlap with the goals of the grant per se.
- Their role as the SCTF is to continue to educate the state on every level on why certain public health measures are necessary to improve the health care of Texans with sickle cell disease, and they are hopeful they can proceed with the work.
- What the SCTF can do if a sickle cell registry bill is refiled next session to address the privacy concerns the Governor mentioned in his veto and having some interim internal conversations take place in Sickle Cell Surveillance Subcommittee meetings.
- For next steps regarding education and support for sickle cell bills next session, DSHS agency staff can work with the SCTF on their member responsibilities and roles as compared to what would be considered lobbying when dealing with legislature rules.

#### **Agenda Item 5: Sickle Cell Task Force Rules**

Dr. Fasipe reviewed with members the Sickle Cell Task Force Rules and reminded members with the passing of HB 1488, the Sickle Cell Task Force Rules would need to be updated through the agency's revision process. Dr. Fasipe referenced the handout, *Adopted Rules*.

#### **Highlights of the presentation included:**

- Highlighting sections on statutory authority, which references the Texas Health and Safety Code, SCTF purpose, and composition.
- Section E on composition will be updated and includes information on term appointments, their staggering and how each term expires on August 31 of that particular year.
- Rules also discuss the SCTF Bylaws, officers, required training, travel, issues related to travel, and date of abolishment.
- The date of abolishment has been extended to 2035.

**Member discussion:**

- Although some members who have been a part of the SCTF for a while will eventually come off because of term limits, being encouraged that the SCTF will have an ongoing life for patients in the state and have a more enduring impact than the Sickie Cell Advisory Committee.

**Agenda Item 6: Bylaws review**

Dr. Fasipe reviewed with members the current Bylaws. Dr. Fasipe reminded members that the bylaws will need to be updated with the passage of HB 1488 and stated that members will consider SCTF-proposed amendments in an upcoming meeting. Dr. Fasipe referenced the handout, *Sickle Cell Task Force Bylaws 11-10-2021*, then led members in a discussion to propose amendments.

**Highlights of the presentation included:**

- Emphasizing sections one, four, five, and seven.
- Section one deals with the abolishment date, which they will extend by 10 years.
- Section four deals with task force composition, which will be updated to reflect HB 1488.
- Section five deals with member terms, and section seven discusses officer positions of Chair and Vice-Chair.

**Member discussion:**

- Due to the unusual situation the last two years with some unexpected resignations, the appointment of two new members who are at their first meeting, and the addition of new members after September 1, weighing a proposal to amend Section Five on member terms to include a conditional statement to allow the members whose terms end August 31, 2023 to have a one-year overlap with new members.
- Concerns over the number of members whose terms are up in 2023 and having an overlap with new members so they could help new members get settled.
- Clarifying current member terms and expiration dates.
- Valuing current members' experience and supporting the idea that those with experience on the SCTF remain, for least a period, to share their experience with newer individuals on the SCTF.
- Impact of the COVID pandemic and other circumstances on the SCTF and using conditional language, such as "as needed," so the extension of terms limits is not set in stone.
- How to phrase proposed amendments.
- While the Bylaws include a statement that a member can continue to serve if their replacement has not been found, it is hard to guarantee, so it would be helpful to have an additional statement for the purposes of extension in a situation where 50 percent of the committee might be new.
- If any member categories include a physician who specifically provides medical care for patients with sickle cell disease.
- If no one can be found to fit a member category such as a physician specializing in hematology, since there are so few in the state, if that would allow current physicians to remain on the SCTF.
- Because of the mandate around education, if the SCTF could consider making one of the positions more specific to an academic teaching hospital in the state of Texas.
- HB 1488 language cannot be changed but can be interpreted in different ways.
- Members are not a part of the selection and appointment process.
- To address that there are not a lot of physicians in Texas who care for patients with sickle cell disease, more senior physicians might consider taking the responsibility of

mentoring and encouraging junior faculty in various institutions and inviting them to join and apply.

- If there is a pathway to changing the number of members that constitute a quorum in the Bylaws.
- Whether an amendment is needed to make sure members understand they need to comply with the expectation of attending the meetings and participating on subcommittees, especially with the impact resignations have made on the SCTF's ability to be effective.
- Improving member accountability for missing SCTF and subcommittee meetings.

#### **ACTION ITEMS:**

- Program staff will clarify when current member terms expire and provide guidance on how new members terms will be staggered.
- Members will work on amendment phrasing and submit it to program staff to add to the draft Bylaws so that DSHS and HHSC staff can review and approve by the August meeting.
- Program staff will draft a paragraph to bylaws membership section that states, "in the event of 50 percent turnover in one task force year, extend the terms of existing members for up to one year."

#### **Agenda Item 7: Newborn Screening Program updates**

Dr. Fasipe stated there were no updates at this time.

#### **Agenda Item 8: Sickle Cell Surveillance Subcommittee reporting**

Dr. Fasipe introduced Dr. Melissa Frei-Jones, Subcommittee Chair. Dr. Frei-Jones referenced the handout, *Sickle Cell Surveillance Subcommittee Meeting Minutes, July 6, 2023*.

#### **Highlights of the presentation included:**

- A recap of the Sickle Cell Surveillance Subcommittee meeting on July 6.
- While Dr. Frei-Jones has been a subcommittee member since the SCTF initiated it, and Dr. Johnson joined when she joined the SCTF, and Mr. Harris was able to join the meeting for first time; members spent some time bringing Mr. Harris up to speed on what the subcommittee has been trying to do to gather pieces of data needed for a surveillance program.
- The subcommittee had previously gotten a report on 2019 Medicaid data, and the manager of the Health Services Team, Data Dissemination and Reporting, was there in follow up of a request for a presentation on 2020 Medicaid data.
- The information was like the 2019 data in terms of the number of individuals on Medicaid, prescriptions filled for hydroxyurea, penicillin prophylaxis prescriptions, and transcranial doppler ultrasound orders and completion.
- Data points were chosen because they were part of a national report from the Centers for Medicare & Medicaid Services (CMS) 2017 national Medicaid data reporting on the national sickle cell population, and the subcommittee had requested if the state of Texas could give similar information about their Medicaid population.
- Subcommittee had questions about the data, including some related to whether some of the discrepancies between access to preventive care and access to some of the general medical care were due potentially to race or diagnosis.
- Dr. Frei-Jones had informed subcommittee members that they had Medicaid-only data, mentioned that a Houston group presented to the subcommittee before about establishing an all-payer database in Texas, and stated that hopefully they can invite someone to present some information on sickle cell patients in the all-payer database in the spring.
- Dr. Frei-Jones also updated and informed the subcommittee about the DSHS application for the CDC Sickle Cell Data Collection grant, and that they will hopefully

Sickle Cell Task Force • July 11, 2023 • APPROVED Meeting Minutes\_08\_18\_2023

hear in late summer if Texas was chosen, which will directly inform the contents of their meetings the next year.

- Highlighting the different groups and entities the subcommittee has been working with, including Medicaid, all-payer database, newborn screening, vital statistics, and syndromic surveillance, which had been part of the legislative report for the past several years.
- The subcommittee requested Syndromic Surveillance present their 2022 data, which they hope they can present at the next subcommittee meeting, and the subcommittee can then share with the full SCTF.
- Mr. Harris asked why that based on the Medicaid report, they are seeing a lot of patients with sickle cell disease not getting recommended care, not getting hydroxyurea prescriptions, not getting transcranial color duplex sonography (TCCD), since he is new to the state of Texas and has experience with a different state health system in the way sickle cell patients receive care.
- The Medicaid presenter pointed out Texas has not had a Medicaid services expansion, so the data is primarily children in the system and not adults.

#### **Member discussion:**

- Sharing the information, the Sickle Cell Surveillance Subcommittee received and having a discussion aimed at the Medicaid Contracts Subcommittee in terms of taking the information to DSHS, to Dr. Van Ramshorst, and to the Medicaid Managed Care Organization directors to make an impact on the current insurance program to improve access to these important points in sickle cell care.
- As someone that lives with sickle cell but also working as an advocate, Mr. Harris has lived in states where the state did not expand Medicaid but were able to provide certain Medicaid benefits to adults with sickle cell disease if they received Social Security benefits.
- How do Medicaid benefits for patients with sickle cell disease work in Texas and what are the logistics of (such as to what extent and when) the subcommittee and SCTF being able to make recommendations; there is a further conversation outside of surveillance but should be included in the surveillance conversation too.
- Another state without a statewide surveillance or registry bill was able to get the grant, so there is hope the veto does not have impact on that.
- From a recommendation standpoint, how to help health availability and equity for the sickle cell population without Medicaid expansion.
- Texas Medicaid coverage for people who have applied for Social Security and how that differs in other states.

- Clarifying that Texas Medicaid is mostly for children when it comes to sickle cell disease, and the subset of adults eligible for Medicaid-type coverage or Social Security tend to have another comorbidity.
- It is rare for sickle cell by itself to allow a person to be eligible, with only a few patients with high health care utilization or several hospitalizations sometimes meeting criteria.
- The social worker at Dr. Frei-Jones' facility could run through the eligibility process because she counsels patients, and it is part the transition readiness for patients between ages 18-25.
- Texas Medicaid has buy-in for adults who are not qualified for Medicaid, so there is recognition that some adults may not have sufficient income, allowing them to purchase Medicaid at a reduced rate, which is similar to the Children's Health Insurance Program (CHIP) in the pediatric population.
- A patient with renal failure or dialysis might also qualify for Medicare, so that can occur at a younger age because of renal disease.
- Options could also include marketplace plans and employer-sponsored insurance.
- How sickle cell is not covered by Texas programs such as Children with Special Health Care Needs or those for patients with genetic diseases, but in Michigan, they worked with their legislature to expand some of their similar programs to cover sickle cell patients in the gap of patients who do not qualify for Social Security Income (SSI), who are unemployed, or do not have employer-sponsored insurance to get Medicaid.
- Many Houston clientele are paying out of pocket when they cannot afford to pay for out-of-pocket copays.
- The Sickle Cell Association of Texas Marc Thomas Foundation also has social workers working diligently in the area of Medicaid to ensure families are served.
- The system is challenging, which goes into transition as well.
- If Syndromic Surveillance will be collating information from other entities in their report they will give or if entities will submit data separately.
- If the DSHS receives the grant, the information from various entities will go to DSHS and flow into the data collection system because in other states that have it set up, a centralized group gets Medicaid, all-payer database, and newborn screen data, and they link individual patients through those data sets.

#### **ACTION ITEMS:**

- Invite an expert to the next meeting who could address Mr. Harris' questions about lack of Medicaid coverage for adults with sickle cell more comprehensively and include the topic on the next meeting agenda or have it addressed by the Medicaid Contracts Subcommittee.
- Invite social workers to discuss Medicaid system challenges in more detail so they can share their experiences.

#### **Agenda Item 9: Medicaid Contracts Subcommittee reporting**

Dr. Fasipe presented an update of the Medicaid Contracts Subcommittee and referenced the handout, *Medicaid Contracts Subcommittee Meeting Minutes, June 27, 2023*.

#### **Highlights of the presentation included:**

- At their June 27 meeting, members expressed interest in the Medicaid data and continuing their work in educating the Medicaid medical directors.
- Members reviewed the bills, including the two components that impact Medicaid, which are health care provider education and the role of the new HHSC member position on the SCTF.

- Sickle cell has been added to the agenda for the October 10 Medicaid Medical Director meeting, and plans include a reintroduction and update on education and activities.
- Suggesting a partnership with the Sickle Cell Surveillance Subcommittee to present Medicaid data at the Medical Director meeting.
- The subcommittee will have ongoing conversations with DSHS and the Medicaid team on carrying out HB 1488 activities.
- The subcommittee reflected on how primary care providers and specialists understand and are accountable to their role in providing care to patients with sickle cell disease.
- Continuing a partnership with Dr. Lisa Glenn and Dr. Ryan Van Ramshorst, Senior Associate Medicaid Director and Medical Director for Medicaid and Children's Health Insurance Program (CHIP) to understand Medicaid support, programs, and reimbursement practices through the lens of other rare blood disorders such as hemophilia and the definition and concept of quality sickle cell care.
- Continuing to review guidelines and plans that have reflected sickle cell care in their guidelines and working on getting other plans to follow suit.

Defining the medical home for sickle cell and how the hematologist, primary care provider, and other specialists are linked together. **Member discussion:**

- Reiterating the hybrid opportunity with the Medicaid Medical Directors and sharing Medicaid data.

**Dr. Fasipe announced a 15-minute break at 2:48 p.m.**

**Dr. Fasipe reconvened the meeting at 3:03 p.m. and requested Ms. Buck-Ragland conduct a roll call.**

### **Agenda Item 10: Public Awareness Campaigns Subcommittee reporting**

Dr. Fasipe turned the floor over to Ms. Marqué Reed-Shackelford, Subcommittee Chair, and asked her to present to members the Public Awareness Campaigns Subcommittee Report. She referenced the handout, *Public Awareness Campaigns Subcommittee Meeting Minutes, June 30, 2023*.

#### **Highlights of the presentation included:**

- Subcommittee met June 30 and welcomed new member Ms. Linda Wade; they caught her up on subcommittee activities, including reviewing the status of the University of Texas Human Dimensions of Organizations project.
- Frank Luera, DSHS, presented to the subcommittee on Community Health Workers, sharing information about how they communicate, disseminate announcements, their advisory committee, and continuing education credits.
- Mr. Luera also shared with subcommittee members an opportunity for them to provide additional public awareness to Community Health Worker community by preparing a one-page sheet, which they could share with Community Health Workers in the state for September Sickle Cell Awareness month.
- Members discussed being able to add new members to the subcommittee with the passage of HB 1488.
- Members discussed their recommendations for the 2023 legislative report and agreed to leave the current wording but add and emphasize working with Texas colleges and universities.

#### **Member discussion:**

- How decision making from the subcommittee led to Dr. Fasipe and Dr. Frei-Jones being able to present a DSHS Grand Rounds and that they are waiting for data from that meeting.

- Appreciation of the subcommittee's efforts for annual Sickle Cell Awareness Month and World Sickle Cell Day.
- Recapping the subcommittee's recommendations for the legislative report.

### **Agenda Item 11: Legislatively Mandated Report Subcommittee reporting**

Dr. Fasipe provided a Legislatively Mandated Report Subcommittee update and referenced the handout, *Legislatively Mandated Report Subcommittee Meeting Minutes, April 20, 2023*.

#### **Highlights of the presentation included:**

- Members met April 20 and discussed a plan to draft and finalize the 2023 legislatively mandated report.
- Subcommittee members were grateful for everybody's time, and they are seasoned as the authors of last year's report.
- They met before the legislative cycle decisions but did see some things they could generate in the new report to add on to what they have done in the past.
- How they divided roles and responsibilities.
- Deadline for the first draft is Friday, July 14, and they hope to have an initial draft in time for the SCTF to review before the next SCTF meeting for consideration.
- Possible timelines for updates since DSHS submits the draft in December.

### **Agenda Item 12: 2023 legislatively mandated report development**

Dr. Fasipe provided an update and led a members discussion on the 2023 Legislatively Mandated Report development. She referenced the handout, *2022 Sickle Cell Task Force Annual Report*.

#### **Highlights of the presentation included:**

- Reviewing the Executive Summary and the specific format for state reports, which included the 2022 goals and recommended actions.
- Reminding members of the timelines of the 2022 report.
- Going through the 2022 recommended actions one by one and requesting feedback and updates for the 2023 report.
- Recommended action of extending the SCTF beyond August 31, 2025 was achieved.
- Reviewing the decisions that lead to the recommended action on evaluating options to increase Medicaid and CHIP eligibility for individuals diagnosed with sickle cell disease to age 26.

#### **Member discussion:**

- Whether to keep increasing membership as an ongoing recommended action.
- Agreeing to remove the ask for extending the duration of the SCTF.
- Recommending some edits to identify funding for statewide awareness activities.
- Having the recommended action stay on developing partnerships to allow Texas to apply for the Centers for Disease Control and Prevention Sickle Cell Data Collection Program.
- Editing but keeping recommended action on developing comprehensive medical home models.
- Keeping and updating recommended actions on evaluating options to increase Medicaid and CHIP eligibility and establish and maintaining a universal sickle cell data collection system.
- Clarifying the HB 1488 requirement timeline for the SCTF to incorporate sickle cell education into a recommendation.
- Creating a separate subcommittee directed towards education.

- Why the recommended action language on Medicaid eligibility needs to be updated to include “lifespan eligibility” instead of to “age 26” and if transition language needs to be included.
- Clarifying the SCTF member role in how new laws such as HB 1488 are carried out.
- Why the SCTF should make a recommendation on holding emergency room providers accountable for the care they provide to patients with sickle cell disease and addressing the climate of emergency rooms in Texas and how to phrase it.
- Reviewing the concept of and efforts creating sickle cell centers of excellence as it relates to hospital accountability and quality improvement through a rating or quality system.
- Considering the effectiveness of patient reporting through hospital patient relations or advocacy offices.
- Reviewing emergency medicine education efforts and that discussing how to improve emergency room care through a legislative perspective is within the SCTF future purview.
- Whether SCTF membership could include an emergency room physician that takes care of sickle cell patients.
- Delineating SCTF member recommending versus lobbying.

#### **ACTION ITEMS:**

- Share the link for the American College of Emergency Physicians sickle cell point-of-care tool with members.
- Recommend creating a way for patients with sickle cell disease to file complaints about emergency care, such as through a statewide reporting system.
- Recommend developing a sickle cell quality plan with goals for Medicaid and private insurance plans.
- Revisit for the 2024 report re-recommending a sickle cell registry and mandating sickle cell education and treatment guidelines for emergency room doctors, which also falls in line with creating a quality plan for care.
- Include a sickle cell emergency room care presentation from Dr. Jamie Barner on the next meeting agenda.

#### **Agenda Item 13: Public Comment**

Ms. Buck-Ragland announced that there were no pre-registered public comments received or present for the meeting.

#### **Agenda Item 14: Future agenda items, next meeting date, and adjournment**

Dr. Fasipe reviewed action items from the meeting and then opened the floor for discussion of future agenda items.

#### **ACTION ITEMS:**

- Subcommittees may not have time to meet before the next meeting, so the priority for each subcommittee is to make sure that the legislatively mandated report (LMR) actions and their work are well reflected.
- Review the February 24, 2023, draft meeting minutes and any other minutes available.
- Newborn Screening Unit program updates
- Subcommittee reports
- Texas Medicaid refreshers from the state and a social worker
- Review the 2020 Medicaid data shared with the Sickle Cell Surveillance Subcommittee.
- Rules and Bylaws amendment updates review

- Full review of data sources to include Newborn Screening, Syndromic Surveillance, Vital Statistics, All-Payer Claims Database, and other data for the 2023 SCTF LMR report.
- Emergency department and Medicaid research presentation from Dr. Jamie Barner
- 2023 Legislatively Mandated Report draft review.
- Members will send additional ideas for the 2023 LMR and Bylaws amendments to Program staff in advance of the August 18 meeting, deadline to be determined.
- Presentation by article author of *Sickle Cell Disease: A National Shame*.

**Member discussion:**

- All-Payer Claims data may not be available yet, but the Sickle Cell Surveillance Subcommittee would love to review sickle cell-related data including DSHS Grand Rounds analytics, website visits, and social media campaign engagement numbers.
- Status of presenter requests from previous subcommittee and SCTF meetings.
- Adding agenda items to the next meeting to discuss new subcommittees based on HB 1488 information.

Dr. Fasipe announced the next Task Force meeting will be August 18, 2023, then with no further discussion, Dr. Fasipe, Chair, called the Sickle Cell Task Force meeting to an end at 4:19 p.m.

*Below is the link to the archived video of the July 11, 2023 Sickle Cell Task Force meeting to view and listen for approx., two years from date meeting is posted and in accordance with the DSHS records retention schedule.*

*(To view and listen to the entirety of the meeting click on the link below)*

Webcast recording link: [Sickle Cell Task Force Meeting July 11, 2023](#)