

**Sickle Cell Task Force Meeting
Minutes**

December 01, 2022

12:00 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. Melissa Frei-Jones, presiding member of the Sickle Cell Task Force (Task Force), called the meeting to order at 12:01 p.m. and welcomed everyone in attendance. Dr. Frei-Jones announced that members, Ms. Pricilla Hill-Ardoin and Ms. Alysian Thomas, will be leaving the Task Force. She thanked them for their time they contributed towards the work over the past couple of years for patients with sickle cell disease living in the state of Texas. Dr. Frei-Jones announced a change in the order of agenda items: agenda item 2, Consideration of Draft Minutes for August 19, 2022, would be tabled and presented at the next meeting. Dr. Frei-Jones introduced and turned the floor over to 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 only three members present, the Task Force did not meet quorum.

Table 1. Sickle Cell Task Force member attendance at the Thursday, December 01, 2022 meeting.

Member Name	In Attendance
Dr. Titilope Fasipe	Yes
Dr. Melissa Frei-Jones	Yes
Ms. Priscilla Hill-Ardoin – joined at 12:08	Yes
Dr. Dawn Johnson	No
Dr. Alecia Nero	No
Mrs. Marqué Reed-Shackelford	Yes
Ms. Alysian Thomas, J.D.	No

Yes: Indicates attended the meeting

No: Indicates did not attend the meeting

Agenda Item 2: Consideration of August 19, 2022, draft meeting minutes

Minutes were tabled until the March meeting.

Agenda Item 3: Sickle Cell Task Force Rules

Dr. Frei-Jones introduced and turned the floor over to Ms. Laura Arellano, Unit Coordinator, Texas Department of State Health Services (DSHS), Newborn Screening (NBS) Unit to provide members an update on Sickle Cell Task Force Rules. Ms. Arellano referenced the handout, *Texas Administrative Code, Section 37.420*.

Highlights of the presentation included:

- Ms. Arellano reported that Title 25 of the Texas Administrative Code, Part 1, Chapter 27, Subchapter R, Section 37.420, concerning the Sickle Cell Task Force Rules, were adopted as of September 29th of this year.
- The new rule as listed addresses the statutory authority, Texas Health and Safety Code Chapter 52, purpose of the Task Force, duties, reporting requirements, and membership information. It acknowledges that the Task Force does have adopted bylaws as well as the membership terms, officers, and required training, per ACCO guidance, as well as addresses information about travel and the date of abolishment, August 31, 2025.
- The transition for adopting the bylaws went smoothly.

Member discussion:

- Mrs. Marqué Reed-Shackelford thanked Ms. Arellano for her presentation.

Dr. Frei-Jones advised members that she was returning to agenda item 1 for introductions of the DSHS staff members.

Agenda Item 1: Continued - Welcome, introductions, and logistical announcements

Dr. Frei-Jones called on Ms. Karen Hess, Director, DSHS, NBS Unit. Ms. Hess introduced herself and then called on Dr. Debra Freedenberg, Laura Arellano, Aimee Millangue, and Lori GabbertCharney to introduce themselves.

*Note Ms. Priscilla Hill-Ardoin joined the meeting at 12:08 p.m. and at this time, introduced her presence. Ms. Buck-Ragland informed the presiding member, Dr. Frei-Jones, that the Task Force did meet quorum with 4 members present. Dr. Frei-Jones announced that the Task Force would move onto agenda item 4.

Agenda Item 4: Project ECHO® (Extension for Community Healthcare Outcomes)

Dr. Frei-Jones introduced Ken Fraser, Outreach Manager, Project ECHO®, University of New Mexico Health Sciences Center to present to members Project ECHO. Mr. Fraser referenced the PowerPoint and handout, *ECHO Intro: Creating a Virtual Community of Practice*.

Highlights of the presentation included:

- **Project ECHO** is a learning platform that creates a virtual community of practice.
- How Project ECHO started, what the purposes are, and what the model looks like.
- Dr. Sanjeev Arora, a gastroenterologist, started Project ECHO at the University of New Mexico about 20 years ago after a patient who lived 250 miles away from Albuquerque was unable to visit his office every 2-6 weeks for treatment had died, and eventually came up with a way to train clinicians out in the front lines of the communities in New Mexico to identify and treat and administer Hepatitis C treatment.
- His idea was based on how he learned how to be a gastroenterologist, by presenting cases to his professors and his professors would talk about it in a group, basically in grand rounds, and the training could be done through a video conferencing session.
- Mission is not only to share knowledge but democratize the best practices for health care and education to underserved people around the world, and the platform has grown beyond the areas of medical and health care, into education, into civics, and a number of different areas around the world.
- The model for Project ECHO is a hub and spoke with the hub at the center of it and spokes are the community providers.
- Project ECHO does not work directly with patients but looks to maximize and multiply the effect of the "spokes," the frontline community providers, teaching complex processes through guided practice where there is input and interaction.

- The hub consists of four main roles, information technology support (managing the video conference), ECHO lead facilitator, ECHO program coordinator, and subject matter experts.
- The ECHO model has four principles: to use technology to leverage scarce resources, share best practices to reduce disparities, apply-case-based learning to master complexity, and evaluate and monitor outcomes.
- Project ECHO differs from telemedicine because experts are working with the clinicians, and that multiplies in that each one of the clinicians impacts their patients, instead of interacting with patients one-on-one.
- Project ECHO has a large network of partners, who they offer a Project ECHO Resource Library, support, their platform, and a free Zoom license.

Member discussion:

- The Health Resources and Services Administration funded a regional demonstration program for sickle cell disease in 2017 that allowed five regional ECHOs to start, but since it has a regional approach, Task Force members are working on how to figure out how to scale it for a big state like Texas, where someone from a small town may not have the ability to link up to a bigger regional one, a super hub.
- How to build a sickle cell ECHO for Texas that reaches rural clinicians.
- Whether Project ECHO works with partners who are not necessarily clinicians, such as insurance companies, so they can learn about a disease and improve care for their patient populations, but it is not available for commercial use.
- What funding models other ECHOs have.
- Project ECHO does not supply grants to fund ECHOs because partners must find their own funding, but their partner training discusses how to get grant funding and budget and they have a grants team with expertise on helping partners find grants.
- The Heartland Network has spin-off ECHOs that focus on specific areas such as advance practice providers, pediatricians, and emergency department.
- If program staff have seen an ECHO-type of model applied at a state level.

ACTION ITEM:

- Mr. Fraser will connect the Task Force to other ECHO staff who could walk the Task Force through how to build relationships between the regional areas.

Agenda Item 5: 2022 legislatively mandated report status

Dr. Frei-Jones introduced Ms. Aimee Millangue. Ms. Millangue reminded members that they received an electronic copy of the 2022 Legislatively Mandated Report and referenced the handout, *2022 Sickle Cell Task Force Annual Report*.

Highlights of the presentation included:

- Report was published on the DSHS website under legislative reports sometime in November and was sent out to Task Force members.
- A lot of what was voted upon at the August 19 meeting is still in the report with some verbiage changes and simplification of the language, such as to reflect some of the language used in the 2021 report.
- Final proposed recommended actions.
- Some information in the appendices were removed, but the report includes a link to the Texas Syndromic Surveillance report presented at the August 19 meeting.

Member discussion:

- Timeline of when the report would be presented to the Executive Council, legislators, and various offices.
- Where the Syndromic Surveillance report is linked in the annual report.

ACTION ITEM:

- John Chacon will look back at ACCO’s schedule to see when the Sickle Cell Task Force report is up for the Executive Council to review.

Agenda Item 6: Sickle Cell Surveillance Subcommittee reporting

Dr. Melissa Frei-Jones, presiding member and Subcommittee Chair, stated that the Sickle Cell Surveillance Subcommittee was unable to meet between the last meeting and now, so there is no report.

Member discussion:

- None

Agenda Item 7: Medicaid Contracts Subcommittee reporting

Dr. Melissa Frei-Jones, Presiding Member stated that the Medicaid Contracts Subcommittee was unable to meet between the last meeting and now, so there is no report.

Member discussion:

- None

Agenda Item 8: Public Awareness Campaigns Subcommittee reporting

Dr. Melissa Frei-Jones, Presiding Member stated that the Public Awareness Campaigns Subcommittee was unable to meet between the last meeting and now, so there is no report.

Member discussion:

- None

Agenda Item 9: HDO (Human Dimensions of Organizations) project

Dr. Frei-Jones turned the floor over to Ms. Millangue to update members on the Human Dimensions of Organizations (HDO) Project. Ms. Millangue referenced the PowerPoint and handout, *Human Dimensions of Organizations Project*.

Highlights of the presentation included:

- A team worked with the Task Force throughout the Fall 2022 Semester and presented their final presentation on November 17.
- The program is looking into what information from their presentation and final report could be available for the next public meeting in February.
- Quick project summary
- Members of the student research team
- The students stated their task was to increase awareness of sickle cell on college campuses, create dialog on college campuses around sickle cell in conjecture with family planning, and connect the Sickle Cell Task Force with organizations capable of a potential partnership.
- Primary research methods

- Students developed four recommendations: form partnerships, have in-person outreach events, have a social media presence, and create merchandise.
- List of organizations at the University of Texas and Huston-Tillotson University and medical schools with whom the Task Force can form partnerships, such as minority student medical professions organizations and student medical centers.

Member discussion:

- Public Awareness Campaigns Subcommittee members shared their impressions of the final presentation
- The student comments during their final presentation showed how very necessary public awareness is on the subject of sickle cell because they commented how much they learned about sickle cell and how much they did not now, and how much they benefited from what they were able to learn in the process, and if the Task Force could expand that to the broader community impacted by sickle cell or even others interested in it, it just shows the impact of good public awareness.
- Public Awareness Campaigns subcommittee members did not get a chance to ask many questions of the students after their presentation, and they wished they could have engaged with them more.
- The recommendation on student organizations could crossover to other student organizations at colleges and universities throughout Texas.
- Looking at working with HDO in future semesters to answer more questions.
- Clarifying that they created a plan for achieving the tasks, but the tasks are not actually done yet.
- In a future semester, could the project be actually trying to build the partnerships and completing the tasks, or if the HDO students have a solely advisory or consultive role.
- The students who worked on the project have reached the end of their program, so another subset of students will be in the class the next semester.
- If undergraduate fraternities and sororities, especially those that have more minority populations, came up – not just those that were medical-based.
- How the Task Force could move forward with the recommendations.
- If the HDO student work could be shared with other entities, such as the student National Medical Association chapter at the medical school where Dr. Frei-Jones is on the faculty.
- Membership of the Public Awareness Campaigns Subcommittee.
- The presentation addressed questions such as the best time to send out social media messages and the specifics of building a social media campaign.
- The Task Force will not pursue a spring 2023 HDO project.

ACTION ITEMS:

- Program staff will share the recording of the presentation and final report with Task Force members when they are available and research what actions DSHS can take on the recommendations.

- If feasible, the Public Awareness Campaigns Subcommittee can schedule a debrief with Dr. Amy Nathan-Wright and students and have two subcommittee meetings before the February meeting, with the second to discuss next steps.

Agenda Item 10: Public Comment

No public comment was received for this meeting.

Agenda Item 11: Future agenda items, next meeting date, and adjournment

Dr. Frei-Jones stated the next meeting is scheduled for February 24th, 2023 and opened the floor for discussion of future agenda items.

Member discussion:

- Consideration of August and December meeting minutes
- Subcommittee reports
- Presentation or discussion related to the HDO project and invite Dr. Amy Nathan-Wright
- Review of the final HDO report
- Legislative update of any and all sickle cell-related bills
- Member attendance at meetings
- State-based ECHO presentation from the Child Psychiatry Access Network. University of Missouri, or other program
- Sickle Cell Data Collection grant opportunity
- Whether Ms. Priscilla Hill-Ardoin could continue to serve on the Task Force and subcommittees once she officially moves to another state.
- Dr. Frei-Jones volunteering to fill the vacancy on the Public Awareness subcommittee due to Ms. Hill-Ardoin relocating.
- Whether new members will be appointed by the February meeting to fill vacancies.

ACTION ITEM:

- Ms. Millangue will send a formal request to the ACCO Facilitation inbox for Mr. John Chacon to consult with legal counsel and ACCO director regarding membership questions.
- The Medicaid Contracts Subcommittee will explore Medicaid possibilities for an ECHO program.
- Subcommittees will include on their agendas a discussion of 2023 plans.

With no further discussion, Dr. Frei-Jones, presiding member, called the December Sickle Cell Task Force meeting to an end at 2:49 p.m.

Below is the link to the archived video of the October 28, 2022 Community Health Worker Advisory Committee 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 December 01, 2022](#)