

New York State Department of Health

Health Equity Council

March 7, 2025 - Meeting Minutes

Attendees	Council Members: In person: Mario R. Ortiz, Luis (Freddy) Molano Virtually: Alberto J.F. Cardelle, Sara Boerenko, Partial Attendance/Logged in late: Tandra LaGrone, Helen Arteaga (cameras not on) Council Members with an excused absence: Council Members without excused absence: Ngozi Moses, Mill Etienne, Guillermo Chacón, Raul Vazquez, LaRay Brown, John R. Pamplin II New York State Department of Health Office of Minority Health and Health Disparities Prevention (OMH-HDP) Staff: Wilma Alvarado-Little, Olivia Ash, Alice Spina New York State Department of Health Staff: Kristina Usack, Wagner Barbara D. Sykes, Stephanie Gagnon, Avani Pathak, Carolyn Perry, Virginia Sack
Call to Order: <i>Mario Ortiz: Presiding Chair</i>	The meeting was convened at 10:03 A.M. Chair, Mario Ortiz, RN, NP; PhD; FNAP, FAAN, introduced himself and welcomed fellow council members for this year's first in-person meeting. Dr. Ortiz calls meeting to order and provides a review of the agenda. Chair Mario Ortiz introduced himself and welcomed fellow council members for this year's first in person meeting. Dr. Ortiz welcomed Ms. Alvarado-Little, Director of the Office of Minority Health and Health Disparities Prevention. Dr. Ortiz thanked the public for their participation and asked that any suggestions, remarks, or information they wish to share is during the public comment period of the agenda.
Council Business	Dr. Mario Ortiz, Chair provided: Moment of silence for Ms. Lenora Reid-Rose Overview of the agenda Dr. Ortiz facilitated council voting: December 6, 2024, Health Equity Council meeting minutes: Freddy Molano state motion for approval. Ms. Sarah Boerenko seconded that motion – there was no quorum – Ad hoc meeting will be held at a later date.
	Updates: Ms. Alvarado-Little, Director for the Office of Minority Health and Health Disparities Prevention (OMH-HDP) provided updates on the small-scale wellness initiatives including: - Cancer action – Celebrate woman who are in various stages of cancer. Funded to have a retreat in honor of Women's Health History Month. The retreat will celebrate influential women from Rochester - Capital Districts Latinos – Capital District Latinos Food Pantry serves as a resource for low-income residents in the West Hill neighborhood of Albany NY. 99.5% of the participants experience economic difficulties and have an earned income of approximately \$34800 yearly.

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	• United Way of Dutchess Orange Region – day of sharing events – doing surveys and collection demographic information to better understand the community’s needs • Mt. Vernon Neighborhood Health Center – focused on oral health for children, teens and adults. They will also distribute bags of nutritious food to the community • United Way of Rockland County – 2 days of comprehensive medical screenings for their communities, includes blood pressure checks, breast cancer risk assessments, • Chinese Community Center – senior mental and physical health initiative, participants involved in one of two informative seminars featuring both Chinese and Western medicine • NYSDOH-led initiatives include the following: NYS American Indian Health Program (AIHP) funding initiatives focused on dental efforts, organizing language access report which supports the NYS Language access law, demographic data collection toolkit, Asian American and Pacific Islander legislation – disaggregation of data • April is Minority Health Month – OMH-HDP will host celebrations next month (April) via a four-part virtual series of panel presentations.
Sickle Cell Legislation <i>Suzanne Swan, Director, Bureau of Child Health</i> <i>Alice Spina, Public Health Fellow III, Office of Minority Health and Health Disparities Prevention</i>	Listening Sessions: Ms. Spina began with an overview of community listening sessions. She summarized the Council members preferences based on surveys conducted in preparation for today’s meeting. This approach serves to learn how they would like to use community listening sessions to fulfil requirements of the legislation. She then deferred to the Chair to continue the discussion. Suggested listening session topics from the surveys focus on how New York State can: • Educate the public regarding sickle cell disease and the benefits of early detection. • Establish a statewide public health education and outreach campaign to publicize events based on sickle cell disease screening, detection, and education services. • Develop health care professional education programs and • How the council be more helpful like in messaging to the commissioner and other Albany offices Updates: Ms. Swan provided a robust presentation on the activities related to the state sickle cell legislation. As discussed in previous meetings, the Bureau of Child Health held two listening sessions that asked experts/providers/allies/or patients about their experiences. Areas of focus were screening and early detection, public education and outreach, education for health care providers, counseling and referral services, promoting health and quality of life/improve system of care and data collection.

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Council Next Steps	Action Items: • Vote on meeting minutes from 12/06/24 at the next Council meeting due to lack of quorum at today's meeting. • Create a timeline of investigation for sickle cell, Artificial Intelligence and woman's health. • Due to lack of a quorum, Dr. Ortiz, Ms. Alvarado-Little, Dr. Arteaga and Ms. Spina will meet to layout the timeline. This timeline will be presented to the Council members during a meeting to be scheduled prior to the June meeting. • Provide recommendations to the Commissioner of Health by December 2025.
Meeting Recap, Feedback, Action Items and Next Steps	Dr. Ortiz thanked the Council for a great discussion. Next steps include creating a sickle cell disease timeline of investigation and recommendations to the Department of Health and the Commissioner of Health. The Council is in the planning a development stage, the goal is to provide recommendations to the commissioner by the end of 2025.
Public Comment and Adjournment	Ms. Alvarado-Little opened the meeting for public comment. Question: How can we ensure that patients with sickle cell are being treated equitably in the ER as too often patients are neglected and left unattended for hours, if not days with a condition that only worsens the longer, we stay in a crisis. And how do we hold professionals accountable for not taking care of patients? and following company federal guidelines? Response: Suzanne - far beyond my expertise, but I can just pivot here – there is a need to include provider education in our recommendations to the Commissioner of health and perhaps not limit it to our ER physicians. Include Medical schools, there needs to be more hands - on training, hands - on education for all providers of all levels throughout their careers. Dr. Ortiz then asked if there is some way we can work with NYSED to get an assessment of what content they are teaching.
	Comment: Even when made aware of the malfeasance that were conducted by negligent professionals, our cries as sickle cell fall on deaf ears, even though under 42 USC 1986, they have an obligation to prevent neglect once made aware. Since the implementation of the VICP and CICP, the numbers of negligent situations have increased as doctors and other health professionals are protected by a void, ab initio, established immunity. When a patient with sickle cell disease says, I have a 50 % chance when I go to the hospital that someone will be nice to me. How are we addressing that experience?
	Question: I would like to discuss a patient experience form that I have developed to change the culture of health systems towards individuals with sickle cell disease. Response: Dr. Ortiz responded that the Council only makes recommendations to the Commissioner. So yeah, so I mean, we can find an answer to this, and then, but like right now, it doesn't seem to be the top priority that for us to work on that. But once again, this council only makes recommendations to the commissioner in light of the legislation.

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	Question: I feel like going to the doctors is a waste of time and energy, as it seems that the doctors nowadays just brush through their cases instead of taking their time to help, instead of taking their time to explain how to help. Maybe it's burnout, lack of passion. It doesn't make me want to trust my provider. Response: I do think that some of these comments can be very easily rolled up with the feedback that we've received so far and into that provider education piece, but also based on the last comment, perhaps the reimbursement piece as well
	Question: The complaint form is not about the disease. It's about the treatment of individuals with the disease. Response: Please send form to omhhdp@health.ny.gov for review.
	Question: Why are doctors allowed to use hospital policies instead of following federal guidelines like the Patient Bill of Rights to facilitate care? Response: It's hard to answer that why question- there are federal guidelines that must be enforced.
	Question: Why do patients with sickle cell disease now describe themselves as sickle cell warriors. What does it say when an individual human being is potentially halfway through their life expectancy has to be a warrior? Cystic fibrosis or leukemia patients don't have to be warriors. Frankly, it's because they are African American. Response: Dr. Ortiz responded that he wasn't sure if there's an answer to that, but I think that could go part of into the data that Ms. Swan's that group has been collecting in terms of the patient experience that's tied to living with sickle cell. We keep sort of hearing the same theme now of that they're having difficult experiences, they are discriminated against, and don't the proper or appropriate care that they should have.
	Question: Before 2020, we were allowed guests in the emergency room. The guests for sickle cell patients are advocates and need to be allowed 24-7 access. Response: From my understanding, in general, a lot of health care systems, if you ask, they will allow you, depending on what the unit is. If it's ICU or critical care, that may not be 24 -7. But if you ask for more access, they usually give it to you. It'd be interesting to see what other health care leaders would recommend.
	The meeting adjourned at 11:10 AM.

Next Meeting Date
June 13, 2025

Time
10:00 a.m. – 1:30 p.m.

Location
Albany, NY