New York State Department of Health
Health Equity Council
September 13, 2024 - Meeting Minutes

Attendees	**Council Members:** In person: Mario R. Ortiz, LaRay Brown, Alberto J.F. Cardelle **Virtually**: John R. Pamplin II, Ngozi Moses **Partial Attendance:** Tandra LaGrone, Helen Arteaga- Landaverde **Council Members with an excused absence:** Sara Boerenko, Guillermo Chacón, Mill Etienne, Luis (Freddy) Molano, Raul Vazquez, Diane Holt, Lenora Reid-Rose **Council Members without excused absence: N/A** **New York State Department of Health Office of Minority Health and Health Disparities Prevention Staff:** Wilma Alvarado-Little, Olivia Ash, Alice Spina **New York State Department of Health Staff:** Jamie Spina (Division of Legal Affairs), Suzanne Swan, Carolyn Perry, Kristina Usack, Stephanie Gagnon, Michele Caggana
Topics	**Discussion**
Call to Order & Introductions ***Mario Ortiz:*** *Presiding Chair and* ***Dr. Helen Arteaga-Landaverde:*** *Former Presiding Chair*	**The meeting was convened at 10:05 A.M.** • Chair, Mario Ortiz, RN, NP; PhD; FNAP, FAAN, introduced himself and welcomed fellow council members for this year's third in person meeting. Dr. Ortiz welcomed Associate Commissioner, Ms. Alvarado-Little from the Office of Minority Health, and Health Disparities Prevention, Helen Arteaga-Landaverde PhD; MPH, Alberto J.F. Cardelle, PhD; MPH, John R. Pamplin II, PhD; MPH, Tandra LaGrone and Ngozi Moses MSc. 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. Ortiz, Presiding Chair provided:** • Agenda Overview • Public Health Law 243 Sickle Cell: Disease Detection discussion • Dr. Ortiz facilitated Council voting items: ○ June 7th, 2024, Health Equity Council meeting minutes: Ms. LaGrone stated motion for approval. Ms. Moses seconded that motion. Council approved, no opposing, no abstentions. ○ Vice-chair nominations. According to the bylaws, the Council, shall nominate a Council member in good standing to the vice-chair position with the goal of better supporting incoming Chair, Dr. Ortiz. If there is more than one candidate nominated, the voting can be submitted via email to Associate Commissioner, Wilma Alvarado- Little since

she is not a voting member- wilma.alvarado-little@helath.ny.gov. Ngozi Moses nominated Dr. Helen Arteaga for Vice Chair and Ms. Tandra LaGrone seconded the nomination. There were no other nominations. The council voted for Dr. Arteaga to be Vice Chair. All in favor, no opposing, no abstentions.

Associate Commissioner, Ms. Alvarado-Little provided updates for the Office of Minority Health and Health Disparities Prevention.

Wilma highlighted Olivia Ash and Alice Spina roles within the Office of Minority Health and Health Disparities Prevention and Health Equity Council. The Office has contracted with Capital District Latinos to sponsor events during Hispanic Heritage month. The goal is to promote better health outcomes through better prevention, detection, treatment, and education efforts within the Latino community. Their presentations are done in a culturally competent and linguistic way. It addresses areas of inclusivity and belonging to our communities. Events are open to the public on October 13th and 15th of 2024 from 11-4 PM.

- October is Health Literacy Month. Office of Minority Health and Health Disparities Prevention is sponsoring two organizations to share how they have addressed health needs in plain language and health literate ways. Members of academia will share the intersections of health literacy with Artificial Intelligence (AI) and machine translation as it impacts our communities with disabilities.
- Office of Minority Health and Health Disparities Prevention has partnered with State University of New York Albany Center for the Elimination of Minority Health Disparities to host a data symposium on November 8th, 2024. The symposium will highlight best practices in demographic data collection and utilization.
- The office has submitted the New York State Department of Health Language Access Plan in support of New York State Language Access Law.
- Office of Minority Health and Health Disparities Prevention continues to oversee the American Indian Health Program, which is supported by New York State Public Health Law § 201(1)(s). The program focuses on dental care and health related initiatives.
- In 2023, Office of Minority Health and Health Disparities Prevention was awarded the Health Disparities Centers of Disease Control and Prevention (CDC) Grant that continues to support LGBTQ+ work groups. The office partnered with the AIDS Institute to form a LGBTQ+ Work Group.
- In 2021, racism was declared as a public health crisis and that established the Racial Equity Working Group in New York State. Those who are interested in participating in a subcommittee and learning more about the working group are asked to contact the office at the following email address OMHHDP@Health.NY.Gov

Updates and Presentation: Sickle Cell - S1839A / A2609 *Suzanne Swan, Director, Bureau of Child Health* *Alice Spina, Public Health Fellow III, Office of Minority Health and Health Disparities Prevention*	**Sickle Cell - S1839A / A2609 Updates and presentation:** **Updates:** Ms. Suzanne Swan, Director of Bureau of Child Health in the Division of Family Health in the Department of Health oversees a sickle cell program that funds five hemoglobin specialty care centers that transition patients from pediatric to adult care for youth ages 14-21. Along with the Council, Ms. Swan, and her team provide research and recommendations to the Health Equity Council and New York State Commissioner of Health. Ms. Swan updated the Council that stakeholder engagement meetings are planned for the end of September, and she will report back with recommendations. **Presentation:** Ms. Alice Spina presented the requirements in the Sickle cell legislation to the Health Equity Council. The Health Equity Council is advising the Commissioner of Health on statutory obligations related to sickle cell disease, focusing on health equity by promoting screening, public education, and counseling services, especially for underserved populations. Their recommendations include establishing a statewide outreach campaign, providing grants, compiling data on sickle cell disease, and developing education programs for healthcare professionals. Other states like California, Florida, Georgia, New Jersey, and Texas have initiated various programs for sickle cell disease treatment, education, and awareness, showcasing diverse approaches to addressing the disease. At the federal level, efforts include research, data collection, and the introduction of new therapies, alongside international initiatives in countries like Canada and India aimed at improving care and eliminating sickle cell disease as a public health issue. **Discussion:** • Dr. Arteaga inquired about the best practices that were brought up in the presentation, specifically Canada. Since 2023, Canada has called for framework to address training, education, diagnostic, and treatment tools needed by healthcare professionals. They also have created a research network to advance and improve data collection and establish a national registry. Canada is creating a national standard for the diagnosis and treatment of sickle cell to provide equitable access to neonatal screening, diagnosis, and the provision of results to individuals living with sickle cell. Canada is constructing a public awareness campaign and analysis regarding the implementation of a tax credit for people living with sickle cell disease and their caregivers. • Ms. Swan states that Department of Health has not implemented any of the practices discussed regarding Sickle Cell outside of New York State, her team is not large enough to accommodate. The Newborn Screening program is a tool that has been utilized for 50 years. • Dr. Arteaga wants to investigate Canada's program to see if there is assist or resources available on program implantation. • Ms. Brown would like to know existing ideas withing New York State Department of Health and the Federal government regarding sickle cell disease programing.

	• Ms. Alvarado-Little answered, the charge of the legislation is to provide the Commissioner of Health with recommendations for the state of New York. The purpose of the presentation was to level set knowledge of sickle cell for all Council members. Council has been working on this statute recently to be added to legislation. • Ms. Brown noted that since 2023, the United States Food Drug Association (FDA) had approved two gene therapies. The council should work to make the therapies widely available to individuals with sickle cell disease, especially for individuals from low-income communities. She advised that New York State should explore how to expand Medicaid benefits to ensure that people have access to gene therapies. The second recommendation is educating Department Clinical Staff on sickle cell disease, especially regarding sickle cell pain crises as patients have experienced being wrongfully labeled as drug seeking. She recommends that this training educates providers and reduces that stigma towards patients' and their needs. The goal is to promote community-based resources that are available for individuals living with sickle cell disease. She would like to have local community forums regarding sickle cell. • Dr. Ortiz added that it is important for the council to make recommendations based on the current standards of care. • Ms. Moses agreed with Ms. Brown. She specifically mentions increasing education to health officials in hospitals in identifying individuals with sickle cell so that it does not go unrecognized in communities of color. • Dr. Ortiz agreed and reiterated the importance of establishing the standard of care to ensure patients are treated quickly. He also agreed that community listening sessions are important because the lived experience of patients should inform the decision that the council makes. • Ms. LaGrone inquired about who is going to design and execute the listening sessions. The goal is to create a plan of action regarding sickle cell disease since people of color have been misrepresented when being diagnosed with sickle cell. She would like to create a timeline for when the listening sessions are approved. • Dr. Cardelle inquired if the Council members or public understands the widespread practice of screening availability for sickle cell. He would like to know if screening is available not just in communities of color, but in rural communities. • Ms. Swan stated that screening is available for all communities, but the pricing is determined by insurance. • Ms. Gagnon mentioned the Newborn Screening program screens all newborns for sickle cell disease. • Ms. Brown inquired if families of newborns are referred or given resources to help with sickle cell. She also inquired about eligibility requirements for medical centers. • Within the Newborn Screening program families are given resources once a newborn is diagnosed with sickle cell. The Newborn screening team will provide a map for the sickle cell centers within New York State. There is no long term follow up or registry for families.
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 and development stage, the goal is to provide recommendations by the end of 2025.

Public Comment and Adjournment	Dr. Ortiz opened the floor to public. No comments or emails were made by the public. Ms. Ngozi recommends discussing the Maternal Morality Review Board research and recommendations to the December meeting agenda. Ms. Alvarado- Little asked the information regarding the research be sent to OMHHDP@Health.NY.Gov for review. **The meeting adjourned at 12:30 PM.**

Next Meeting Date	**Time**	**Location**
December 6, 2024,	**10:00 a.m. – 1:30 p.m.**	**New York, New York**