



State of Louisiana

Louisiana Department of Health
Office of Public Health

LOUISIANA SICKLE CELL COMMISSION

December 6, 2022 2:00 – 3:30 PM

Location:

LDH Bienville Building, Room 118
628 North 4th Street, Baton Rouge, LA 70802

Link for public viewing:

<https://ldhophbfhgenetics.zoom.us/j/87826735559>

Phone: 602-333-0032 Conference Code: 532143

1. Welcome & Introductions
2. Roll Call & Attendance
3. Membership Appointment Update
 - a. Review of vacancies
4. Officer Elections
 - a. Nominations
 - b. Elections
 - c. Seating of the new Chairman & Vice-Chairman
5. Report: Data and Surveillance
 - a. [House Bill No. 968](#)- establishes a state sickle cell disease registry
 - i. Provide feedback on the conceptual framework and purpose of the registry
 - ii. Review of relevant LDH data sources for potential use to inform the registry
 - iii. Discuss materials available/needed to establish a toolkit for:
 1. Schools/school based-health centers
 2. Emergency departments
6. Report: Medical Service/Delivery
 - a. [Senate Bill No. 298](#)- annually review medications, forms of treatment, services for care of Medicaid enrollees with SCD
 - i. Discussion to identify new medical service or delivery needs
7. Report: Patient Navigation
 - a. [House Concurrent Resolution No. 76](#)- expresses support for equitable access to transformative therapies for sickle cell disease
 - i. Update: Patient Navigation deliverables incorporated into contracts
 - b. [Senate Concurrent Resolution No. 66](#)- address regulatory barriers that impede patient access to novel therapies for sickle cell disease; have access to potentially curative therapies.
 - i. General discussion & recommendations
8. Report: Education and Advocacy
 - a. [House Bill No. 163](#)- creates the “Sickle Cell Disease Association” specialty license plate
 - i. General discussion & recommendations

OFFICE OF PUBLIC HEALTH

Genetic Diseases Program

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9. Awareness Events
10. Other Business
11. Adjournment