

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

Minutes

1. Welcome & Introductions

2. Roll Call & Attendance

- a. Present in person:
 - i. Donna Thaxton, Northeast Sickle Cell Anemia Foundation
 - ii. Rosalind Spain, Sickle Cell Disease Association, Northwest Louisiana Chapter
 - iii. Erin Fulbright, Sickle Cell Association of South Louisiana
 - iv. Chris Archinard, Southwest Louisiana Sickle Cell Anemia, Inc.
 - v. Cheryl Harris MPH, OPH Genetic Diseases Program (LDH Designee)
 - vi. Hon. Tammi Phelps, Louisiana House of Representatives
- b. Absent:
 - i. Majed Jeroudi, M.D., LSU School of Medicine (attended virtually)
 - ii. Renee Gardner, Children's Hospital
 - iii. Amina Rafique, M.D., Sickle Cell Center of Southern Louisiana-Tulane University School of Medicine
 - iv. Shannon Robertson, RN, BSN, Louisiana Primary Care Association
 - v. Hon. Regina Barrow, Louisiana State Senate
 - vi. Chauncey Hardy, Sickle Cell Anemia Research Foundation, Inc.
- c. Members of the public, in person attendees:
 - i. Amanda Perry
 - ii. Gloria Smith
 - iii. Alishia Vallien
 - iv. Shay Hardison
- d. Members of the public, virtual attendees (from Zoom attendance list):
 - i. Amy Zapata
 - ii. Bridgette Pierre
 - iii. Dr. Paemela Saulsberry
 - iv. Janeace Voorhies
 - v. Jim Nickel
 - vi. Karen Kosinski
 - vii. Molly Taylor – Healthy Blue
 - viii. Rihana Galloway-Dawkins
 - ix. Tyler Craddock – Bluebird Bio
 - x. Ernest DeJean

3. Membership Appointment Update

- a. Review of vacancies
- b. The commission has a vacancy of a person diagnosed with sickle cell disease.

4. Officer Elections

- a. Nominations
- b. Elections

- c. Seating of the new Chairman & Vice-Chairman
 - i. No action was taken on electing a chairman and vice-chairman because an in person quorum was not present.

5. Report: Data and Surveillance

- a. House Bill No. 968- establishes a state sickle cell disease registry
- b. Amanda Perry gave an update on the following:
 - i. 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
 - ii. The commission requested feedback from Medicaid on the assessment of sickle cell treatments available to affected patients.

7. Report: Patient Navigation

- a. House Concurrent Resolution No. 76- expresses support for equitable access to transformative therapies for sickle cell disease
 - i. Cheryl Harris informed the commission that Patient Navigation deliverables were incorporated into the sickle cell foundation 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 (hospital access) – Amanda Perry
 - ii. Discussion was held about hospital access to patients and HIPAA.

8. Report: Education and Advocacy

- a. House Bill No. 163- creates the “Sickle Cell Disease Association” specialty license plate
 - i. General discussion & recommendations
- b. Amanda Perry provided an update on educational outreach activities through the LDH Bureau of Media and Communications

9. Awareness Events

- a. Attendees announced upcoming events related to sickle cell disease.

10. Other Business

- a. Discussions were held regarding the following:
 - i. HIPAA release forms
 - ii. Emergency department wait times
 - iii. Collaboration with LDH and the sickle cell foundations
 - iv. Registry development

11. Adjournment