

**LOUISIANA SICKLE CELL COMMISSION MEETING
May 9, 2023 2:30 – 3:30 PM**

Location:
LDH Bienville Building, Room 173
628 North 4th Street
Baton Rouge, LA 70802

Link for public viewing:
<https://ldhophbfhgenetics.zoom.us/j/88115201640>

**Phone: 602 333 0032
Conference code: 532143**

Minutes

1. Welcome & Introductions

Cheryl welcomed everyone to the meeting and introduced Rodney Goldsmith as the new Genetic Diseases Program Strategy Manager who will be responsible for facilitating the LSCC moving forward.

2. Roll Call & Attendance (LDH facilitator)

Attendance was as follows:

COMMISSIONER	ORGANIZATION	PRESENT/ABSENT
1. Renee Gardner, M.D.	Children’s Hospital-New Orleans	Present
2. Amina Rafique, M.D.	Sickle Cell Center of Southern Louisiana-Tulane University School of Medicine	Absent
3. Shannon Robertson, RN, BSN	Louisiana Primary Care Association	Absent
4. Donna Thaxton	Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.	Present
5. Jerry Paige (Proxy for) Rosalind Spain	Sickle Cell Diseases Association, Northwest Louisiana Chapter	Present
6. Chris Archinard	Southwest Louisiana Sickle Cell Anemia, Inc.	Present
7. Erin Fulbright	Sickle Cell Association of South Louisiana	Present
8. Shay Hardison	Sickle Cell Anemia Research Foundation, Inc.	Present
9. Cheryl Harris, MPH	Secretary of the Department of Health Designee	Present

10. Hon. Regina Barrow	Louisiana Senate	Present
11. Hon. Tammy Phelps	Louisiana House of Representatives	Present
12. Rajasekharan Warriar, M.D.	Ochsner Health Center for Children, medical professional who provides treatment and care to patients diagnosed with sickle cell disease	Absent
13. Majed Jeroudi, M.D.	Ochsner LSU Health Shreveport, medical professional who provides treatment and care to patients diagnosed with sickle cell disease	Absent
14. Vacant	Person Diagnosed with Sickle Cell Disease	Absent
15. Shaleathia Campbell	Parent of a person diagnosed with Sickle Cell Disease	Absent

A quorum was present to conduct official business.

3. Officer Elections (LDH facilitator)

- a. Nominations for Chairman
 - i. Erin Fulbright was nominated, voted in and seated as chairman.
- b. Nominations for Vice Chairman
 - i. Donna Thaxton was nominated, voted in and seated as vice chairman.

4. Review and approval of minutes (Chairman)

a. Minutes from the previous LSCC meeting dates listed below were voted on and adopted:

- i. May 9, 2023
- ii. August 15, 2022
- iii. December 6, 2022
- iv. February 7, 2023
- v. March 2, 2023

5. LSCC Commissioner Vacancies (3 total) (Chairman)

- a. (1) Medicaid Director or designee – Cheryl Harris will reach out to Medicaid to obtain names of candidates.
- b. (2) Persons living with SCD – Rodney Goldsmith will check on the application of a person living with SCD who filled out paperwork.

6. Report: Data and Surveillance (Chairman)

- a. Information regarding the CDC funding opportunity (Rodney Goldsmith, Genetic Diseases Strategy Manager (update from Amy) – Rodney discussed a CDC grant OPH applied for that would provide funding and guidance for establishing a database.

b. Update on the Skyler Cooper Database (BFH)- Cheryl gave an update on the Sickle Cell Registry survey that was sent to stakeholders.

7. Report: Medical Service/Delivery (Chairman)

a. review data reports and identify care gaps that may be able to be addressed through Medicaid and/or public health (Business Plan) –

The commission is requesting that Medicaid provide finalized data to review and to be used to make recommendations for patients' services to LDH.

8. Report: Patient Navigation (Chairman)

a. Sickle Cell Follow-up Monitor – The Genetic Diseases Program is hiring a program monitor to render follow-up for sickle cell diseases and to ensure that parents are aware of trait results in newborns.

b. Hospital/ER data sharing/patient navigation

c, Funding for patient navigation

9. Report: Education and Advocacy (Chairman)

a. Emergency Provider Toolkit, Victoria Alexis, BFH Communication Operations and Strategy Manager (Update) – Victoria presented a toolkit designed for ER medical providers to develop a protocol in each hospital ED for sickle cell pain management.

b. Webinars (Re-recording and September – Sickle Cell Awareness Month) – The Genetics Program would like to re-record the toolkit for schools due to technical difficulties. The program is also planning a webinar for Sickle Cell Awareness month in September.

c. Campaign for awareness and education through LDH social media (happy presence) – The commission is asking if OPH has the financial and creative resources for this project.

10. Other Business (Chairman)

a. Discussions, if any

- Response for Chris Archinard (whether EP SW is a recognized org) OPH is waiting on a response from LDH Legal.
- Karen Gant inquired about a standard treatment plan among medical providers. She will send examples from other states.
- Dr. Corey Hebert offered to assist however necessary in his role as a CBS medical correspondent.

11. Awareness Events (Chairman)

a. LSCC Commissioners provide dates/details of upcoming events

12. Adjournment (Chairman)

It was motioned and seconded to adjourn the meeting.