

LOUISIANA SICKLE CELL COMMISSION MEETING

February 7, 2023 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

Minutes

1. Welcome & Introductions

Amanda Perry welcomed commissioners and guests and called roll.

2. Roll Call & Attendance

COMMISSIONER	ORGANIZATION	PRESENT/ABSENT
1. Renee Gardner, M.D.	Children's Hospital-New Orleans	Absent
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	Present
4. Donna Thaxton	Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.	Present
5. 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. Chauncey Hardy	Sickle Cell Anemia Research Foundation, Inc.	Absent
9. Cheryl Harris, MPH	Secretary of the Department of Health Designee	Present
10. Hon. Regina Barrow	Louisiana Senate	Absent

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	Present

A quorum was not present to vote on a Chairman and Vice-Chairman

3. Membership Appointment Update

- a. Review of vacancies – A clarification was made on the total number of seats (17).

According to R.S.1125.1, vacancies exists for the Medicaid Director or designee and for two persons diagnosed with sickle cell disease.

- b. Functions of the commission were reviewed.

4. Officer Elections –

Elections were not held because a quorum was not present.

5. Report: Data and Surveillance

An update of the Sickle Cell Registry and the Sickle Cell Disease Steering Committee was provided.

6. Report: Medical Service/Delivery

Amanda Dumas, M.D., Associate Director of Louisiana Medicaid presented an annual review of Medicaid coverage for sickle cell disease per the “Lorri Burgess Law” (Act 670, RS 2022).

7. Report: Patient Navigation

Information was provided on support to the foundations from Geoff Nagle with Alliance Strategic Advising and Research.

The commission discussed receiving information for patients with sickle cell disease and funding for sickle cell disease.

The commission asked that the Families Helping Families model is shared with the foundations.

8. Report: Education and Advocacy

An update was provided on work with the LDH toolkit. Commission members discussed the commission would like to be added to the toolkit such as information regarding emergency department visits, standards of care, training webinars, etc.

The Bureau of Family Health is working with the Louisiana Hospital Association regarding access to sickle cell patient information within regional hospitals.

9. Awareness Events

No upcoming events were noted.

10. Other Business

Per R.S. 1125.1, five commission members asked to call a special meeting to vote on a new Chairman and Vice-chairman.

11. Adjournment