

LOUISIANA SICKLE CELL COMMISSION MEETING

March 2, 2023 1:00 – 3:30 PM

Location:

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

Link for public viewing:

Public may attend in person

Agenda

1. **Welcome & Introductions**
2. **Roll Call & Attendance** (LDH facilitator)
 - a. LDH facilitator will call the meeting to order if a quorum is present in person
 - i. Meeting called to order
 - ii. **Quorum not present**
 1. 5 present, 12 absent (9 needed for quorum)
3. **Officer Elections** (LDH facilitator) (**quorum not present; no elections held**)
 - a. Nominations for Chairman
 - i. Elections
 - ii. Seating of the new Chairman
 - b. Nominations for Vice Chairman
 - i. Elections
 - ii. Seating of the new Vice Chairman
4. **Review and approval of minutes** (Chairman) (**quorum not present; no voting occurred**)
 - a. From previous LSCC meeting dates:
 - i. May 24, 2022
 - ii. August 15, 2022
 - iii. December 6, 2022
 - iv. February 7, 2023
5. **LSCC Commissioner Vacancies** (3 total) (Chairman)

The vacant positions identified were:

 - a. (1) Medicaid Director or designee
 - b. (2) Persons living with SCD – both Governor appointees

- i. BFH is in the process of developing a process for **the** public to apply for **Boards and Commission positions that will** include informing public of expectations and commitments
 - c. Shane Bates explained the process for seating new members; process involves nominations/recommendations sent to Governor's office; Governor appoints members
- 6. **Report: Data and Surveillance** (Chairman) **(no report)**
 - a. Discuss any decision points regarding the data for the SCD Registry
 - i. Review data points suggested by the Sickle Cell Disease Steering Committee
 - ii. Review data points suggested by the LDH Sickle Cell Disease Guidance Team
- 7. **Report: Medical Service/Delivery** (Chairman) **(no report)**
 - a. Discussions (if any) regarding the Medicaid draft report of covered SCD services
- 8. **Report: Patient Navigation** (Chairman) **(no report)**
 - a. Discussions, if any
- 9. **Report: Education and Advocacy** (Chairman)
 - a. Discussions, if any
 - b. Presentation from Kevin Litten, LDH Press Secretary
 - i. LDH SCD Communications Plan (ppt attached to calendar invite)
 - ii. Audiences: people with SCD, caregivers, school personnel, ED providers
 - iii. School audiences should be: administrators (for 504 eval plans), nurses, teacher, coaches
 - 1. Talking points is a good idea to facilitate dialogue
 - iv. Posters in schools is not a good idea
 - 1. Won't provide much value
 - v. Toolkit will be socialized by whom? In what way? (Link on website)
 - vi. There needs to be some education about the toolkit
 - 1. Bring awareness to school districts in each region
 - a. Ex: students missing b/c of crisis = truancy
 - b. School personnel don't understand SCD
 - 2. Conversation with school administration (school board meeting)
 - 3. Then, school boards share with school leadership
 - 4. School leadership shares with personnel

vii. Media roll out

1. Regional leadership (medical directors)
2. LDH partnerships with LDOE (built relationships with COVID guidance)
3. Foundations' relationships with school leadership
4. Paid: billboard, commercials
5. Partnership with First Lady Foundation/Governor's Office
 - a. Governor film a video for June 19 (World SCD Day)

viii. SAFER cards for SCD patients to use in ED visits

10. Awareness Events (Chairman)

- a. LSCC Commissioners provide dates/details of upcoming events
 - i. June 19 = Juneteenth & World SCD Awareness Day
 1. Requesting LDH promote on social media

11. Other Business (Chairman)

- a. Discussions, if any
- b. BFH will verify Commissioners' contact information: phone, email, address
- c. Future meeting dates/times/locations
 - i. Tuesdays/Thursdays are not good
 - ii. Representative Phelps and Erin Fulbright volunteered to call the LSCC Commissioners to find out which day of the week a meeting is best for them to attend in person. They will report this back to LDH/BFH to facilitate.

12. Adjournment (Chairman)

- a. Motion to adjourn – by whom? Erin Fulbright
- b. Seconded – by whom? Donna Thaxton

Member	Seat information as listed in statute	Attendance
1. Amina Rafique, M.D.	Representative from the Sickle Cell Center of Southern Louisiana, Tulane University School of Medicine *Governor Appointee	Absent
2. Renee Gardner, M.D.	Representative from Children’s Hospital, New Orleans *Governor Appointee	Absent
3. Shannon Robertson, RN, BSN	Representative from the Louisiana Primary Care Association *Governor Appointee	Absent
4. Erin Fulbright, Executive Director	Representative from the Baton Rouge Sickle Cell Anemia Foundation (formerly <i>Sickle Cell Association of South Louisiana</i> as in RS code) *Governor Appointee	Present
5. Donna Thaxton, Executive Director	Representative from the Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc. *Governor Appointee	Present
6. Rosalind Spain, Executive Director	Sickle Cell Disease Association of America Inc., Northwest Louisiana Chapter *Governor Appointee	Present
7. Chauncey Hardy, Executive Director	Sickle Cell Anemia Research Foundation, Alexandria *Governor Appointee	Absent
8. Chris Archinard, Executive Director	Southwest Louisiana Sickle Cell Anemia, Inc. *Governor Appointee	Absent
9. Vacant	Representative for the persons diagnosed with sickle cell disease *Governor Appointee	Absent
10. Vacant	Representative for the persons diagnosed with sickle cell disease *Governor Appointee	Absent
11. Shaleathia Campbell	Representative for the parent of a person diagnosed with sickle cell disease *Governor Appointee	Absent
12. Majed Jeroudi, M.D.	Representative for the medical professionals who provide treatment and care to patients diagnosed with sickle cell disease *Governor Appointee	Absent
13. Rajasekharan Warriar, M.D.	Representative for the medical professionals who provide treatment and care to patients diagnosed with sickle cell disease *Governor Appointee	Absent
14. Cheryl Harris	Secretary of LDH or her designee	Present
15. Vacant	Medicaid Director of LDH or her designee	Absent
16. Senator Regina Barrow	Representative from the Louisiana Senate *Senate President Appointee	Absent
17. Representative Tammy Phelps	Representative from the Louisiana House of Representatives *Speaker of the House Appointee	Present