John Bel Edwards
GOVERNOR

Rebekah E. Gee MD, MPH
SECRETARY

State of Louisiana

Louisiana Department of Health
Office of Public Health

Sickle Cell Commission Meeting
June 11, 2019
10:00 a.m.-12:00 p.m.
https://zoom.us/j/332349063
Conference Call info: (602) 333-0032 or (888) 270-9936
Access Code: 532143#

Roll Call taken by Ms. Burgess; members present at the meeting were as follows:

- Lorri Burgess, Baton Rouge Sickle Cell Disease Foundation – **Commission Chair (via phone)**
- Etta Pete, Southwest Louisiana Sickle Cell Anemia, Inc. (via phone)
- Cheryl Harris, MPH, OPH Genetic Diseases Program (LDH Designee) (via phone)

Additional meeting attendees:
- Jensine Speed, LMSW., Our Lady Of The Lake (via phone)
- Karen Grevemberg, MBA, BSN, RN, United HealthCare (via phone)
- Latarsha Carter, RN, BSN, Healthy Blue
- Michelle Duplantier, LCSW-BACS, OPH Bureau of Family Health (via phone)
- Patti Barovechio, DNP, MN, OPH Bureau of Family Health (via phone)
- Gail Gibson, RN, BSN, MN, CPM, FABC, OPH Bureau of Family Health (via phone)
- Rachelle Boudreaux, MA, OPH Bureau of Family Health
- Kera Simmons, MPH, OPH Genetic Diseases Program (via phone)
- Jantz Malbrue, OPH Genetic Diseases Program

Call to Order
Lorri Burgess called the meeting to order at 10:10 a.m.

Lorri Burgess proposed delaying review of previous meeting minutes and action items until a quorum was reached since there were only 3 commission members in attendance during roll call. Cheryl Harris suggested a review of commission members to ensure their activity and encourage the nomination of appointees for vacant organizations.

Welcome

Approval of meeting minutes – March 26, 2019 (delayed to September 10 meeting)

1. Report: Data and Surveillance- Jantz Malbrue

   Since the beginning of 2019, newborn screening identified 28 newborns with a sickle cell disease diagnosis and 506 newborns were identified with a sickle cell trait diagnosis. The newly identified cases were distributed by regions to the sickle cell foundations and clinics. The Sickle Cell Disease Registry has 2,394 individuals identified through the newborn screening program. The Sickle Cell Trait Registry was created and there are 22,021 individuals identified through newborn screening program with a sickle cell trait diagnosis. Lorri Burgess suggested looking at subset populations like the number of adults in different regions, youth transitioning to adult services, and more.

   CDC Grant Opportunity
   The Centers for Disease Control and Prevention (CDC) recently released a funding opportunity focused on capacity building for sickle cell disease surveillance (CDC-RFA-DD19-1906). The CDC is accepting applications for the fiscal year (FY) 2020. The letter of intent is due June 14, 2019 and the due date for the application is July 22, 2019. The purpose of this program is to improve the lack of consistent scientific data to facilitate informed decision-making that may lead to significant health improvements in the Sickle Cell Disease (SCD) community. Through this Funding Opportunity, the CDC plans to fund up to seven recipients for a one-year period of performance to participate in a rigorous course of activities to build capacity for a state-wide SCD surveillance system. The announcement can be found at https://www.grants.gov/web/grants/view-opportunity.html?oppId=315312.

   Case Management Software
   The OPH Genetic Diseases Program has been working with Social Solutions to acquire their ETO software to be utilized by the Sickle Cell Foundations. Social Solutions is a software company that provides comprehensive case management tools for nonprofits and public sector agencies. The company develops software packages that deliver infrastructure and scalability needed to manage data, share information and track progress. Social Solutions has developed software for other programs within the Bureau of Family Health. The link to their website and software description is https://www.socialsolutions.com/software/eto/.

2. Report: Medical Service/Delivery

   Hemoglobin Gene Testing for Confirmation of Newborn Screening
   In a recent discussion with the OPH Genetic Diseases Program, Dr. Rene Gardner discussed the importance of distinguishing the state of hereditary persistence of fetal hemoglobin (HPFH) in children followed with sickle cell disease. The current standard of care dictates that children with homozygous sickle cell disease should be placed on hydroxyurea at the age of 9 months. Appreciable amounts of fetal hemoglobin are still being expressed at that age and there could be a risk of placing someone on the drug that might not need the medication or benefit from it which is a

dilemma for hematologists. In the past, Dr. Gardner utilized a test to look at Hemoglobin F distribution, but the test is imprecise. Dr. Gardner proposes a better alternative would be the actual testing for the gene, through gene sequencing of either the beta or globin chain. Several laboratories are being contacted to inquire about the algorithm and price for the gene sequencing.

3. Report: Patient/Navigation

Patient Navigator

A meeting has been scheduled with the Sickle Cell Foundations to discuss the current contract for supportive services. The OPH Genetic Diseases Program and the Sickle Cell Foundations will discuss the necessary deliverables, performance measures, and fee scale that would need to be included in order to propose the inclusion of Patient Navigators in the current contracts of the Foundations. The meeting is scheduled for Thursday, June 13 in Alexandria, LA.

4. Report: Education and Advocacy

Website

The OPH Genetic Diseases Program webpages are currently being updated for easier navigation and modern appearance. The Sickle Cell Disease and Louisiana Sickle Cell Commission webpages are being mapped and the content outline is progressing. Once the webpages are finalized, there will be sections for healthcare providers, families, partners, and resources. The same strategy will be applied to the Commission webpage in order to improve online presence.

5. Other Business

   a. 2019 Meeting Schedule

      The remaining meeting dates are scheduled for September 10 and December 10, 2019. Lorri Burgess proposed an in-person meeting for December and the suggestion of a photo of the commission to be included on the website.

   b. Announcements

      - The Sickle Cell Association of South Louisiana will host a press conference and presentation to discuss their HRSA grant partnership with Louisiana Healthcare Connections and World Sickle Cell Awareness Day on June 19. The 2019 Ryan's Run/Walk is scheduled for August.
      - A Shine the Light on Sickle Cell campaign in honor of World Sickle Awareness Day will occur on June 24 in Lake Charles.

- The fourth annual Sickle Cell Awareness Day event is scheduled for Friday, August at Our Lady of the Lake Regional Medical Center in Baton Rouge. The theme of the event is "Tackle Sickle Cell: It is a team effort!"
- The Louisiana Association for Sickle Cell Anemia (LASCA) proposed a statewide client and caregiver retreat for 2019 in Baton Rouge. Details about the event will be shared with everyone once they are finalized.

Adjournment 11:05 AM

Louisiana Sickle Cell Disease Cases

- 28 cumulative sickle cell disease cases have been identified through newborn screening across the state in 2019

Gender	Total	Percent
Male	21	75%
Female	7	25%

Race	Total	Percent
Black	25	89%
Unknown	3	11%

Hemoglobin Disorder	Total	Percent
FS	13	46%
FSC	9	32%
FSA	3	11%
FSE	1	4%
FC	2	7%

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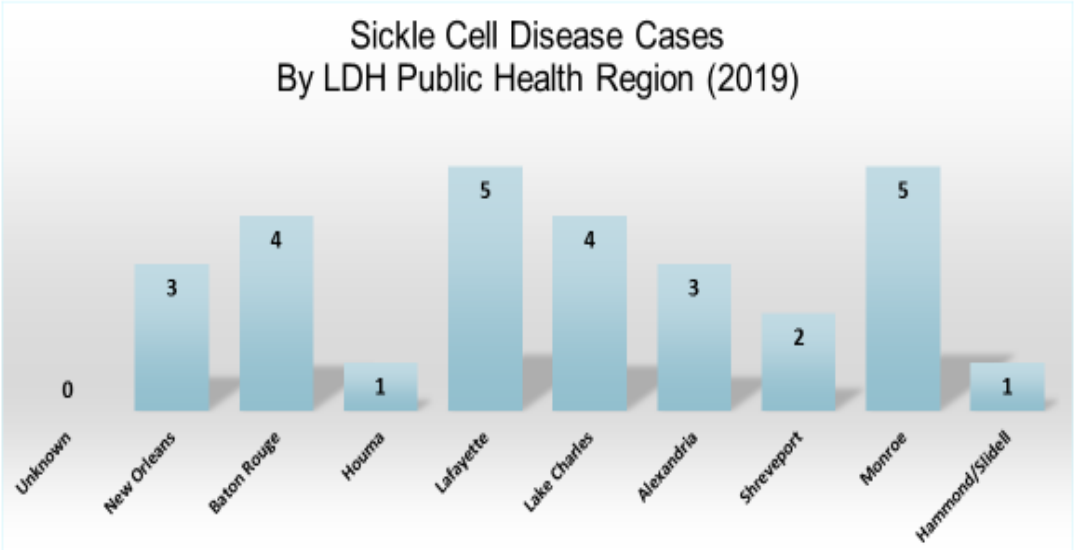
Louisiana Sickle Cell Disease Cases



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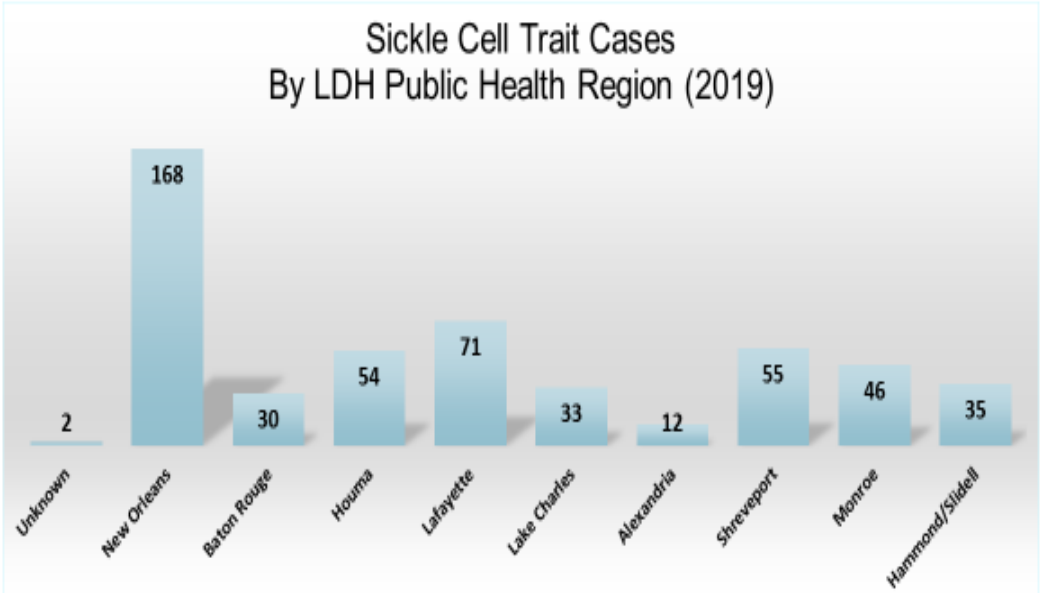
Louisiana Sickle Cell Trait Cases

- 506 cumulative sickle cell trait (FAS) cases have been identified through newborn screening across the state in 2019

Gender	Total	Percent
Male	266	53%
Female	233	46%
Unknown	7	1%

Louisiana Sickle Cell Disease Cases



Louisiana Sickle Cell Registry

1978-2019

- 2,394 cumulative sickle cell disease cases have been identified through newborn screening in the state

Gender	Total	Percent
Male	1,203	50%
Female	1,184	49%
Unknown	7	<1%

Race	Total	Percent
Black	2,274	95%
White	17	<1%
Hispanic	3	<1%
Asian/Pacific Islander	6	<1%
Other	13	<1%
Unknown	81	3%

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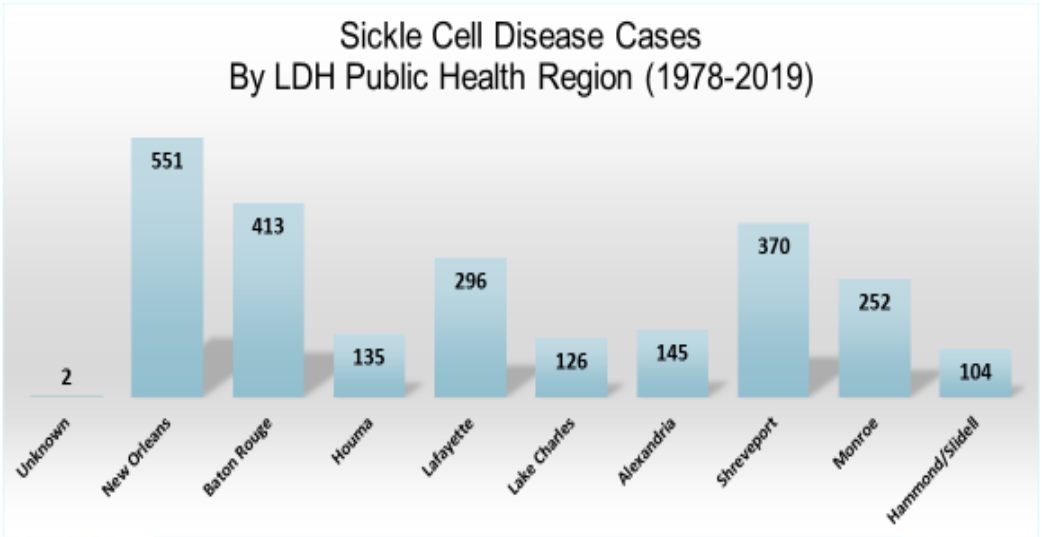
Louisiana Sickle Cell Registry



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Data & Surveillance Workgroup

- Louisiana Sickle Cell Registry
- SCD Medicaid Surveillance System
  - Add DOB, Age, Sex, Race
  - Description for ICD/CPT Codes
  - Medication usage & rate
  - Immunization records
- Data Reporting
  - Increase Visualization (Graphs & Charts)

Medical Services Workgroup

- Finding New Providers
  - Survey PCPs to identify those accepting patients w/ SCD
  - Survey Patients to identify Providers treating SCD
    - Identify Adult PCPs treating SCD after youth transition
- Collaborating with Healthy Louisiana
  - Identify the PCPs receiving the referral for SCD
  - Invitation to meet with Medical Directors
- Emergency Department Education
  - Meeting/Conference with ED Personnel to educate about SCD
- Pain Management Protocols
  - Establish Statewide Protocols for SCD

Patient Navigation

- Patient Navigator Program
  - Negotiate funds into contracts for Foundations
- Chronic Pain Management
  - Introduction of Medical Marijuana
- Know Your Sickle Cell Status Campaign
  - Partner with Universities, Colleges, & other Schools
- Sickle Cell Status ID Cards
  - Educate PCPs about the cards

Education & Advocacy Workgroup

- Statewide Media Campaign
  - Utilize Billboards, Radio, Flyers
  - Expand events outside of September
  - Educate Legislatures
- Know Your Sickle Cell Status Campaign
  - Increase advocacy statewide
  - Educate stakeholders, medical schools, pharmacists, employers
- Website
  - Add Calendar of Events
  - Circulate info to PCPs & Community Advocates
- Sickle Cell Status ID Cards