



State of Louisiana

Louisiana Department of Health

Office of Public Health

Sickle Cell Commission Meeting

May 24, 2022

2:00 p.m.-3:30 p.m.

LDH Bienville Building, Room 118

628 North 4th Street, Baton Rouge, LA 70802

Remote public access option: <https://ldhophbfhgenetics.zoom.us/j/87124362984>

Conference Call info: (602) 333-0032 - Access Code: 532143#

****Please note that with the recent increase in COVID case rates,
masks are requested of all in-person attendees****

Roll Call taken; members present at the meeting were as follows:

- Renee Gardner, MD., Children's Hospital, New Orleans
- Majed Jeroudi, MD., Ochsner LSU Health Shreveport
- Donna Thaxton, Northeast Sickle Cell Anemia Foundation
- Rosalind Spain, Sickle Cell Disease Association, Northwest Louisiana Chapter
- Erin Fulbright, Sickle Cell Association of South Louisiana
- Rajasekharan Warriar, MD., Ochsner Health Center for Children
- Chris Archinard, Southwest Louisiana Sickle Cell Anemia, Inc.
- Cheryl Harris MPH, OPH Genetic Diseases Program (LDH Designee)

Additional meeting attendees:

- Ernest DeJean, Sickle Cell Center-Tulane University
- Raymond Poliquit, MD, Healthy Blue
- LaTarsha Carter, Healthy Blue
- Amanda Dumas, MD., Louisiana Medicaid
- Pamela Saulsberry, PhD., Northeast Sickle Cell Anemia Foundation
- Rachelle Defillo- NOLA Sickle Cell Awareness, LLC.
- Rihana Galloway-Dawkins, Sickle Cell Center-Tulane University
- Dana LeBlanc, MD., Children's Hospital, New Orleans
- Jessica Templet, PA-C, St. Jude Affiliate Clinic, Baton Rouge
- Horatio Handy, Global Blood Therapeutics, Inc.
- Bridgette Pierre, Global Blood Therapeutics, Inc.
- Lisa Tracz, Global Blood Therapeutics, Inc.
- Cherie Hadley, Children's Hospital, New Orleans
- Kelly Hess, Global Blood Therapeutics, Inc.
- Amy Zapata, MPH, OPH Bureau of Family Health
- Amanda Perry, OPH Bureau of Family Health

OFFICE OF PUBLIC HEALTH

Genetic Diseases Program

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"An Equal Opportunity Employer"

- Rebecca Majdoch, OPH Bureau of Family Health
- Rachelle Boudreaux, OPH Bureau of Family Health
- Ayesha Umrigar, OPH Bureau of Family Health
- Jantz Malbrue, OPH Genetic Diseases Program

Call to Order

Jantz Malbrue called the meeting to order at 10:05 a.m.

1. Welcome, Roll Call, & Introductions: Jantz Malbrue
2. Clinical Policy Leadership: Dr. Amanda Dumas
3. Sickle Cell Data to Action and System Transformation: Amy Zapata

Rosalind Spain attended the Black Caucus meeting that occurred last August in Shreveport. She discussed the complications of identifying adult patients with sickle cell to provide supportive services compared to the pediatric population. In addition, Ms. Spain discussed difficulties with gathering information from healthcare providers and the trouble of finding additional funding. Amy Zapata mentioned looking at the why and defining solutions. She discussed promoting the foundation's services and utilizing data to bring in additional funding. Chris Archinard agreed with the need for assistance for exposure of the foundations and that he is having trouble accessing hospitalized patients. Dr. Pamela Saulsberry added that sickle cell remains a public and population issue. In addition, Dr. Saulsberry added that the ID bracelets would assist with triaging patients accessing the emergency department. Ms. Spain stated that patients presenting to the emergency department with a pain crisis are continuously ignored. Ms. Zapata stated the importance of turning voices into recognizable data. She offered to huddle with the sickle cell foundations to discuss concerns and identify next steps. Donna Thaxton shared that her foundation is has progressed with a patient release form that has allowed them to receive patient information from the local hospitals and healthcare providers. Cheryl Harris stated that the commission could request a study resolution or qualitative study to evaluate the treatment of individuals with sickle cell presenting to emergency departments throughout the state.

4. Legislative Reviews and Discussion
 - a. Data and Surveillance:
 - i. [House Bill No. 968](#)- establishes a state sickle cell disease registry
 - b. Medical Service/Delivery:
 - i. [Senate Bill No. 298](#)- annually review medications, forms of treatment, services for care of Medicaid enrollees with SCD
 - c. Patient Navigation:
 - i. [House Concurrent Resolution No. 76](#)- expresses support for equitable access to transformative therapies for Sickle Cell Disease

- ii. [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.

d. Education and Advocacy:

- i. [House Bill No. 163](#)- creates the “Sickle Cell Disease Association” specialty license plate

5. Awareness Events

The Sickle Cell Disease Association of America, Northwest Louisiana Chapter has several upcoming events, including the Be the Match campaign, the Shine the Light event that will include a red spotlight on the courthouse, a radiothon, and their annual softball tournament. The Southwest Louisiana Sickle Cell Anemia is hosting a golf tournament to raise awareness and celebrate Juneteenth. The Sickle Cell Association of South Louisiana is working with the Walls Project and the upcoming unveiling of the healing wall and block party on June 25 in Baton Rouge. Also, Ms. Fulbright added that their sickle cell awareness event known as the Ryan's Run is scheduled for Juneteenth. The Sickle Cell Center at Tulane University is collaborating again with NOLA Sickle Cell Awareness for the Red Run event in September. Dr. Dana LeBlanc added that the sickle cell health resource fair would return in September at Children's Hospital.

6. Other Business

Dr. Majed Jeroudi discussed the thought of having the commission create a standard release of information for collecting client information. Dr. Rajasekharan Warriar mentioned using the project echo platform for providing education for healthcare providers and community partners. Dr. Dana LeBlanc added that Children's Hospital participates in the heartland consortium that hosts monthly meetings.

7. Adjournment

Meeting adjourned at 3:31pm

Momentum: Sickle Cell



Data to drive policy, change in health and supportive systems, and health

Amy Zapata, MPH
Director, Bureau of Family Health
Louisiana Department of Health – Office of Public Health
State Administrator, Social Security Act Title V Maternal and Child Health Block Grant
May 24, 2022

***“Grow
human
potential”***

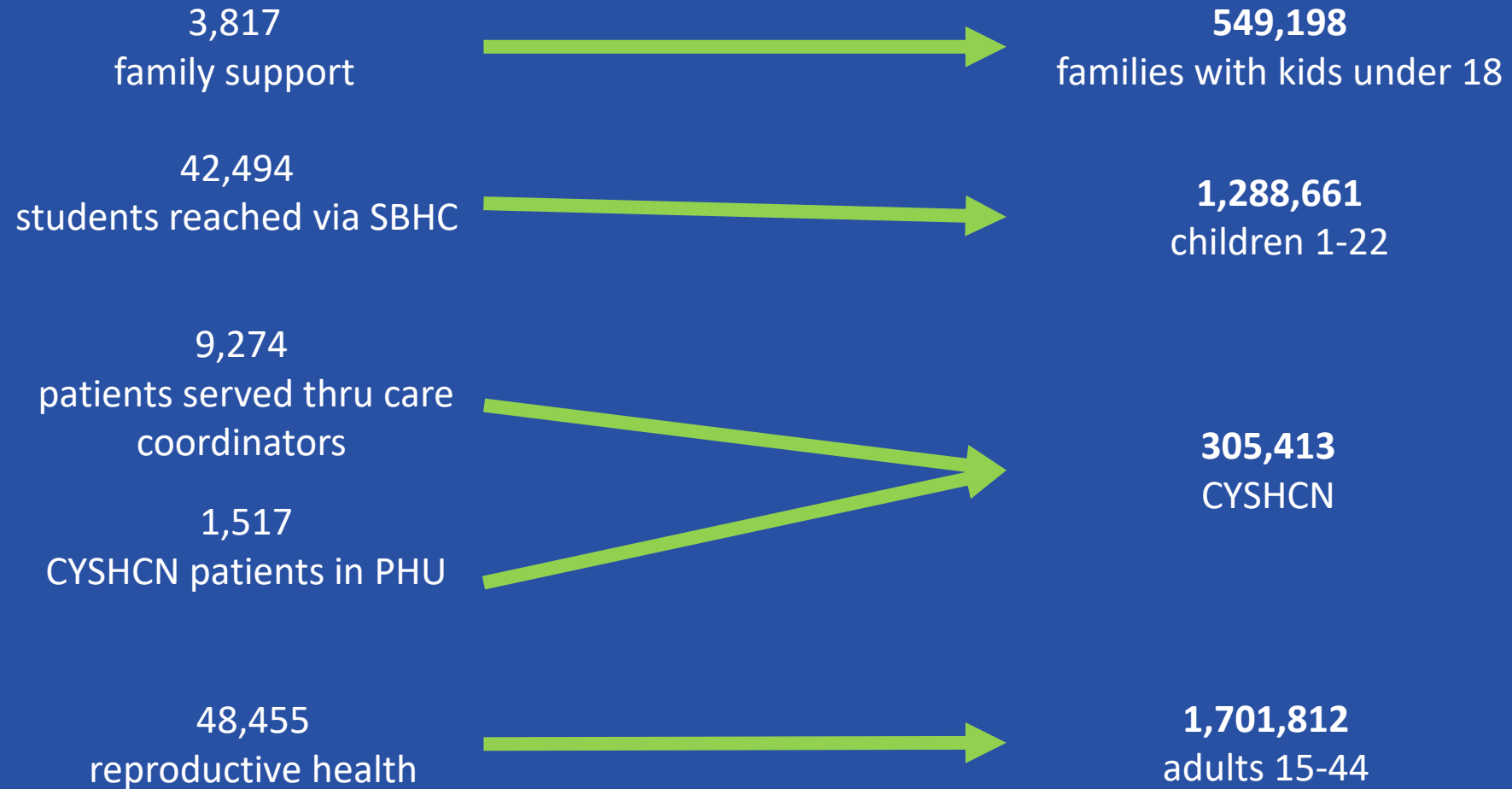
Dr. Michael Lu, 2014

May 19, 2022



The Challenge

The ~~Challenge~~ Opportunity



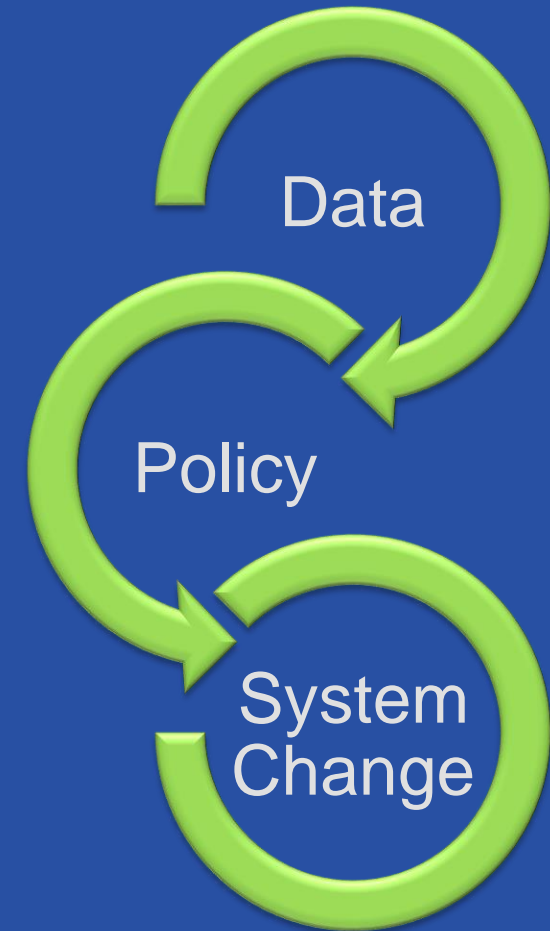
How to reach more people?

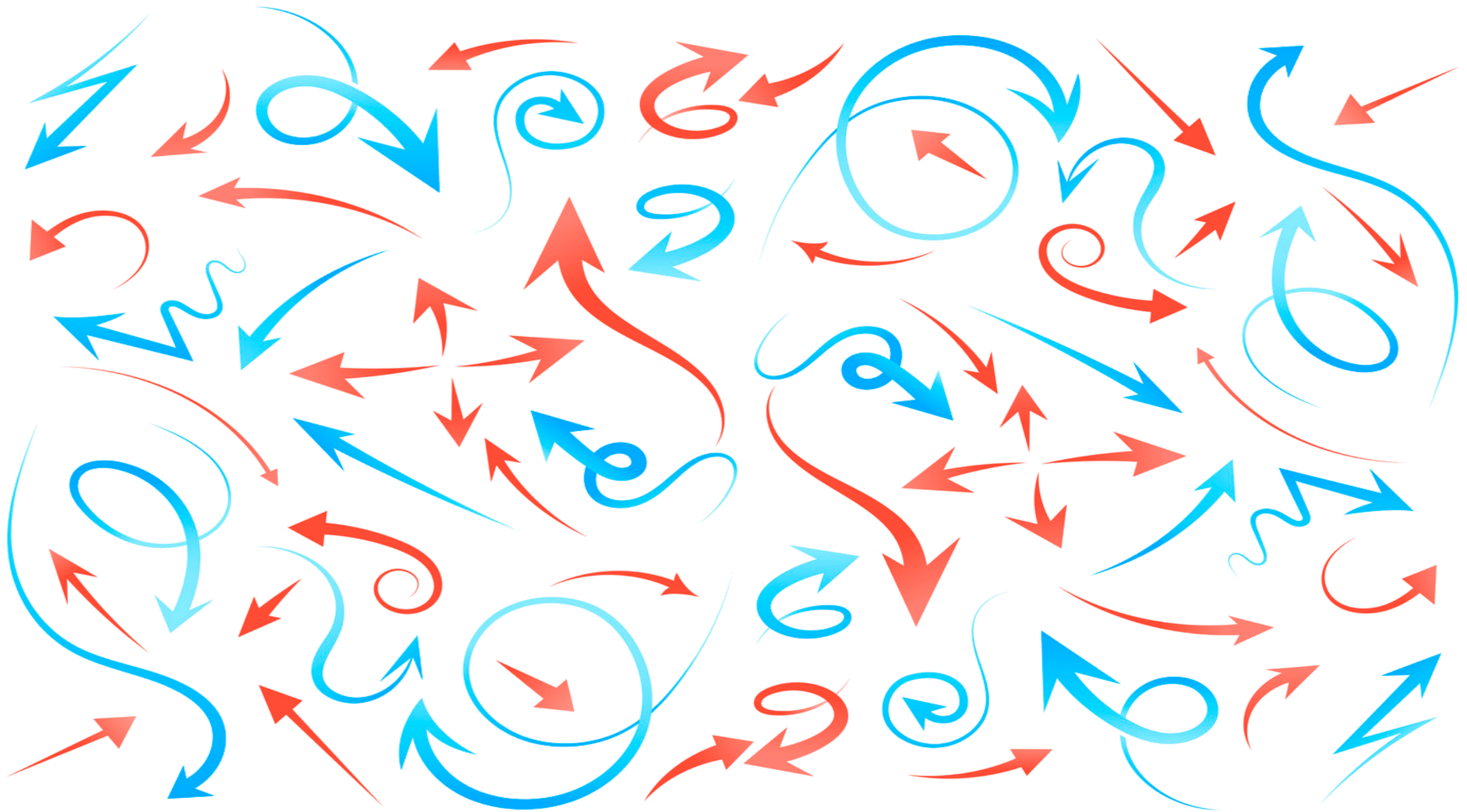
hundreds
and thousands



tens-of-thousands
to millions

Organizational
strategies







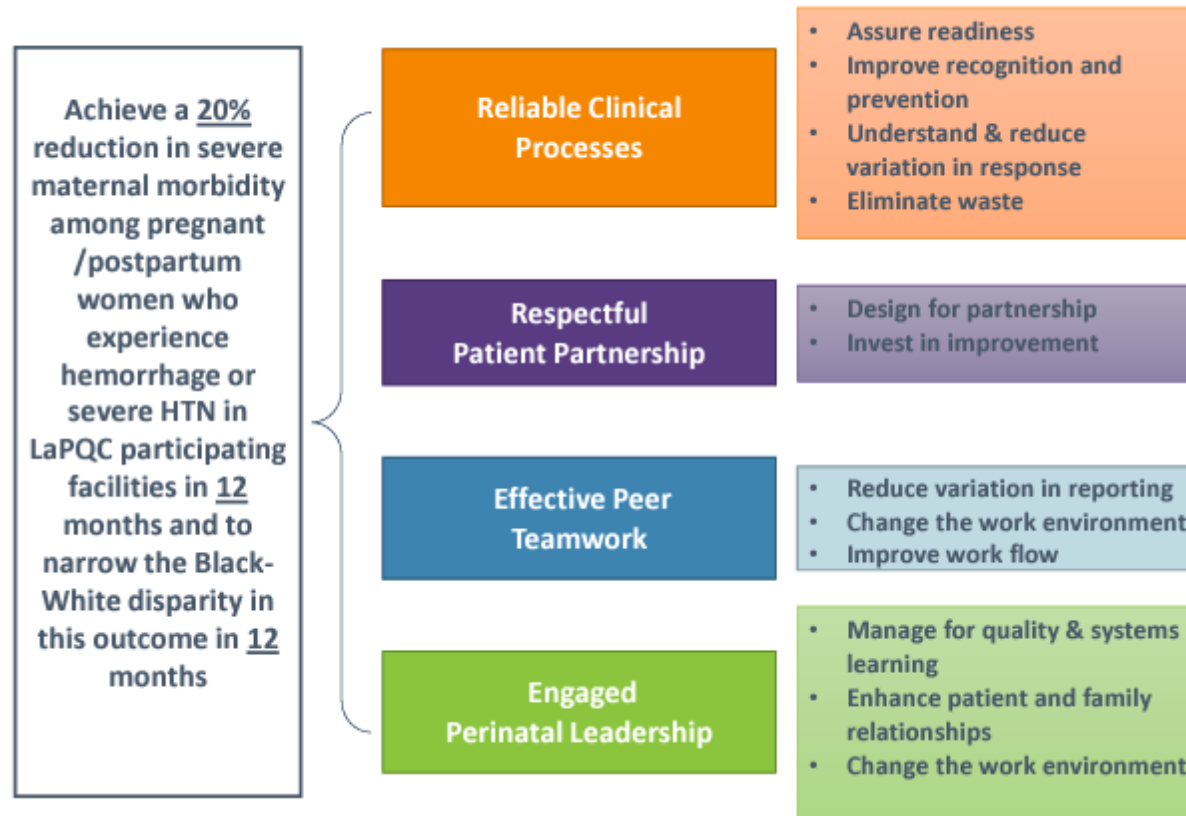
Plans and approaches for boards & commissions under OPH Bureau of Family Health – SFY 23

- Boards and commissions overview
 - All B&C being reviewed to ensure time and efforts are optimized for members
 - Frame in terms of more structured meetings, work groups and reports/deliverables
- (Re-)orientation for all members for all boards, commissions, advisory groups
 - Legislative mandate
 - How that BCC works and member expectations
 - Open meetings requirements and how to make sure we are doing what we need to do (and not doing what we shouldn't do)
 - Ethics (same as above!)
 - Priorities, reports and visibility
- Membership, engagement, meaningful work!

<https://partnersforfamilyhealth.org/boards-commissions/>

Learnings from historical approaches with other boards and commissions: **structured change agenda**

Learnings from historical approaches with other boards and commissions: **structured change agenda**



Transformation applied (example):

Every Mom. Every Family. Every Baby.

- ✓ All individuals who are pregnant or have a baby in Louisiana's birthing facilities can have confidence that Louisiana has ready providers, ready facilities, ready systems and that we are a ready state for **safe birth**.
- ✓ All prenatal and pediatric clinical providers in the state will have the support they need to screen and respond to **critical and emergent concerns affecting maternal health** and the **developmental health of children**.

Why these priorities?

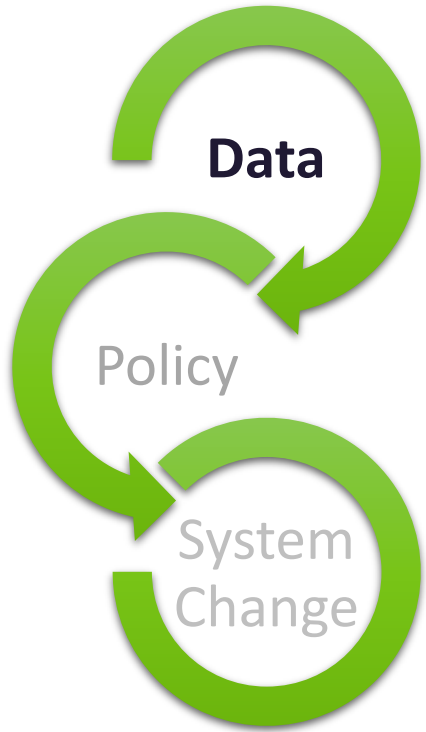
- There is need
- There is momentum (activated systems, activated advocates, activated legislative champions)
- There is enabling policy (more every day) and existing infrastructure that can be scaled and spread

Public health data to inform and clarify needed actions.

Policy that enables and reinforces what we want to see.

Support for our systems to execute.





Public health data to inform and clarify needed actions.

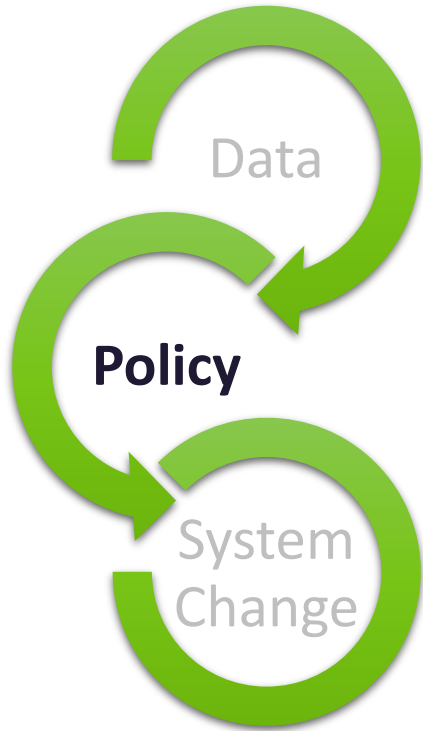
- ✓ Newborn screening and follow up system data
 - ✓ Implementing *Social Solutions* data platform to record information about services provided through the Sickle Cell foundations
 - ✓ Quick run of hospital discharge data to assess feasibility
 - ✓ Quick analysis of ER data to assess feasibility
 - ✓ Matched with national program for epidemiology graduate student for summer
- By September 1, 2022, complete the environmental scan of data currently collected by or reported to the state related to individuals living with SCD.

Policy that enables and reinforces what we want to see.

WOW!!

Legislative actions:

- ✓ [House Bill No. 968](#)- establishes a state sickle cell disease registry
- ✓ [Senate Bill No. 298](#)- annually review medications, forms of treatment, services for care of Medicaid enrollees with SCD
- ✓ [House Concurrent Resolution No. 76](#)- expresses support for equitable access to transformative therapies for Sickle Cell Disease
- ✓ [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.
- ✓ [House Bill No. 163](#)- creates the “Sickle Cell Disease Association” specialty license plate



Policy that enables and reinforces what we want to see.

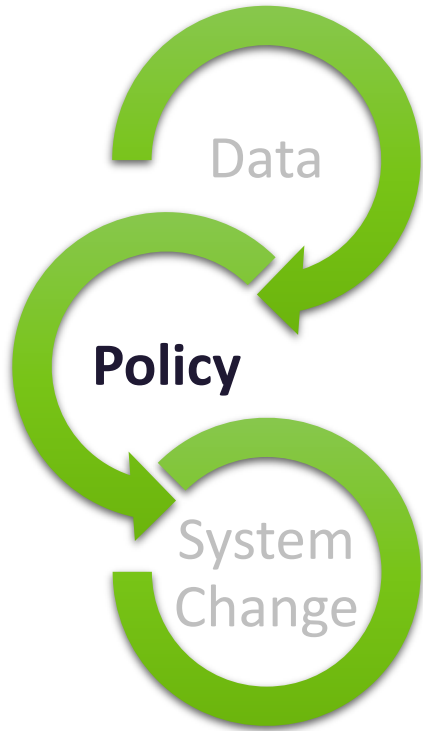
WOW!!

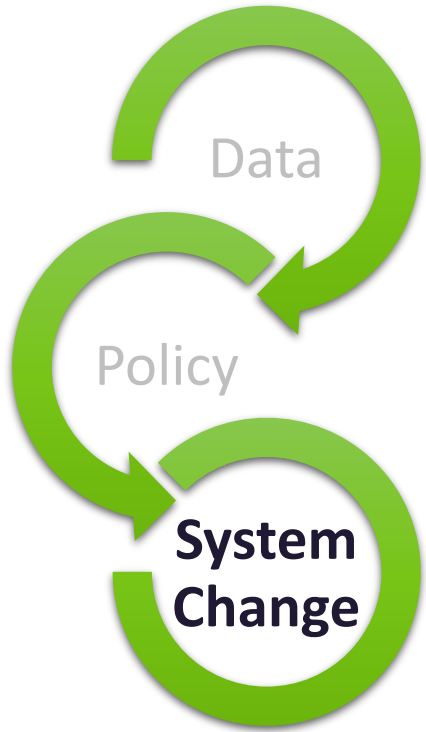
Legislative actions:

- Establishes a state sickle cell disease registry
- Annually review medications, forms of treatment, services for care of Medicaid enrollees
- Expresses support for equitable access to transformative therapies for Sickle Cell Disease
- Address regulatory barriers that impede patient access to novel therapies for sickle cell disease; have access to potentially curative therapies.
- Creates the “Sickle Cell Disease Association” specialty license plate

Internal “policy”:

- ✓ Renewing all Foundation contracts; restructuring to clarify activities and reporting (draft/preview)
 - Newborn follow up
 - Navigation services
 - Data reporting for services
 - Participation in initiatives





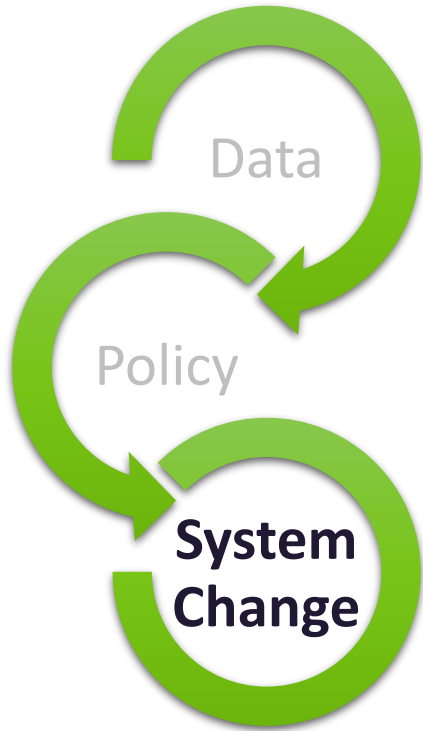
Support for our systems to execute.

All clinical systems and providers in the state will have the support they need to recognize and respond to the healthcare needs of individuals with sickle cell disease (ongoing and urgent)

Support for our systems to execute.

Priority areas (as I understand them)

- Emergency rooms
- Availability of specialists
- Transition from pediatric to adult care
- MCOs?



Change is possible

- Hemorrhage
 - SMM overall: **Decreased by 35%**
 - SMM among non-Hispanic Black persons: **Decreased by 49%**
 - SMM among non-Hispanic white: **Decreased by 16%**
 - Hypertension
 - SMM overall: **Decreased by 12%**
 - SMM among non-Hispanic Black: **Increased by 8%***
 - SMM among non-Hispanic white: **Decreased by 31%**
- *prior to COVID-19 this reduction was 22%

Severe Maternal Morbidity (SMM) includes a range of serious pregnancy complications that result in significant short- or long-term consequences to a woman's health (CDC)

Improving processes, leads to sustained change



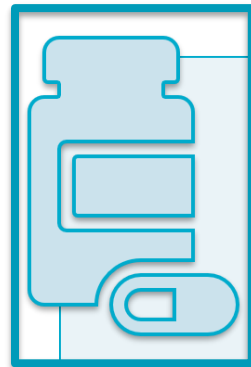
Risk assessment on admission

Increased by 78.3%



Quantification of blood loss at delivery

Increased by 171.8%



Patients receiving timely treatment of hypertension

Increased by 210.8%

See mother's day press release for breastfeeding and c-section progress!